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ABSTRACT

The guide provides some basic strategies and tools for monitoring residential settings--both institutions and community residences--for the quality of services provided to persons with developmental disabilities. An introductory chapter explains the purpose and layout of the document. Chapter II describes how to find and understand public information on institutions and community services. Chapter III discusses two approaches to collecting information on residential settings--the checklist approach and descriptive reports. A fourth chapter deals with independent investigations of events or conditions at institutions and other settings. Chapter V shows how to read and make sense out of individual residents' case records. Chapter VI addresses procedures to identify gaps in community based services; while Chapter VII discusses advocacy strategies used in conjunction with monitoring. An appendix contains the full text of an observational report as an example of descriptive reports. A brief list of resources on monitoring concludes the document. (SBH)

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AUG 14 1980

DD Rights Center

of the Mental Health Law Project and the Center on Human Policy

A GUIDE TO MONITORING RESIDENTIAL SETTINGS

by

Steven J. Taylor

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Prepared by:

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and
The Mental Health Law Project 1980

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The School of Education, Syracuse University

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I want to express my thanks to John McGee for permission to include excerpts from one of his institutional reports in Chapter III.

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Finally, I thank the Bureau of Developmental Disabilities for its support of the DD Rights Center of the Mental Health Law Project with the Center on Human Policy as a national protection and advocacy backup center.

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CHAPTER I. INTRODUCTION

This is a guide to monitoring residential settings -- both institutions and community residences. It is designed to provide you with some basic strategies and tools for insuring the quality of services provided to persons with developmental disabilities.

Why monitor? Why devote the time, energy and resources to being a service-system watchdog? By its nature, monitoring enhances the accountability of publicly-operated or -funded services. Any time you request a public document or inspect a facility, you let officials know that someone is watching what they do. Further, by monitoring, you educate yourself about problems that exist and you learn what needs to be changed. For example, the information you collect can be used as a backdrop for negotiations or as evidence in litigation.

It is important to distinguish between independent monitoring and formal evaluation. Every agency that provides services should be required to meet specific quality standards and be evaluated routinely according to these standards, as a condition of receiving public monies. Thus, a privately operated group home receiving public funds should periodically be inspected and evaluated by the state agency responsible for funding services. You should demand rigorous quality-assurance evaluations of residential settngs in your state or community. One especially useful and effective evaluation tool is PASS (Program Analysis of Service Systems), developed by Wolf Wolfensberger and Linda Glenn. PASS is based on the normalization principle and evaluates services according to normalization criteria.

However, formal evaluation is not a substitute for aggressive monitoring activities on the part of independent advocacy or consumer groups. In the first place, few states or localities impose strict and rigorous standards on publicly funded programs. Too often, standards focus on bureaucratic criteria and ignore quality issues. Secondly, public licensing agencies may lack the staff and resources to conduct thorough program evaluations. The formal evaluation may therefore consist of little more than a "paper audit," or merely the inspection of written policies and procedures. Perhaps it's a sign of the times that an agency may be required to have written policies on abuse, but is not required to prevent it. Thirdly, there is often a conflict of interest between the evaluation agency and the service-providing agency, whether state-operated or privately operated. For example, under pressure to deinstitutionalize, a state may be more interested in moving people out of public institutions than placing them in quality community settings. In any event, you cannot leave it up to states to monitor adequately the quality of services provided to people with disabilities.

There are many ways to monitor programs and service systems. This manual deals with the basic monitoring strategies. Chapter II explains how to find and understand public information on institutions and community services. Chapter III discusses two approaches to collecting your own information on residential settings -- the checklist approach and descriptive reports. Chapter IV deals with independent investigations of events or conditions at institutions and other settings. Chapter V shows how to read and make sense out of individual residents' case records. Chapter VI addresses how to identify gaps in community-based services in your state or locality. Chapter VII discusses advocacy strategies used in conjunction with monitoring. The Appendix con-

tains the full text of an observational report as an example of descriptive reports discussed in Chapter III. Finally, there is a brief list of resources on monitoring.

There are no hard and fast rules of advocacy or monitoring. There are only more or less effective approaches. While the following text offers some general guidelines and describes some strategies which have worked in specific situations, this is not to say there is a single best way to monitor residential services. The intent is not to establish a set of rigid principles, but to share some ideas that some groups have found effective.

CHAPTER II. COLLECTING PUBLIC INFORMATION

Certain kinds of information on services for people with developmental disabilities are collected by public agencies and some of it may be useful in monitoring residential services. For example, you may want to review inspection reports on institutions. Or you may want to compare state expenditures for institutions with those for community services.

Under the Freedom of Information Act, you have a right to review and obtain copies of certain documents and information collected by federal agencies. Many states have similar laws governing state agencies (see Taylor and Biklen, Understanding the Law, published by the DD Rights Center, for information on how to research the law). The following guidelines apply to obtaining public information.

* Check the law to determine whether the information you wish to obtain is defined as a public record. Some items, such as individual residents' or staff members' records, are not public information. Some laws also specifically list other kinds of records that are not public information.
* A public agency is entitled to charge you for the cost of duplicating public documents for your own use.
* You have the right to receive information within a reasonable period of time.
* An agency is not required to collect information for your use. It is only obligated to provide you with information already collected.
* You do not have to explain your purpose in wishing to obtain public information. Do not be intimidated by bureaucrats who demand to know how you will use it.

The sample requests reproduced on the next two pages show that all you need to do is mention that you are making the request under the relevant statute (federal or state) and describe clearly the information you seek.

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ELLEN BARNES
GUNNAR DYBWAD

April 7, 1980

Mr. William Smith
Public Information Office
Office of Mental Retardation and
Developmental Disabilities
44 Holland Avenue
Albany, New York 12229

Dear Mr. Smith:

I am writing to request OMR/DD information under the New York Freedom of Information Law. Please send me the information collected by OMR/DD described below or that which is most closely related.

* OMR/DD expenditure comparisons by developmental center.

* Current figures (not projections) on persons in residential programs, by level of disability and age.

* Current numbers of developmental center residents in day programs by developmental center, age, type of program and level of disability; for residents ages 5-21, numbers in full-time educational programs, part-time educational programs and no educational programming.

* Current numbers of people on waiting lists for state-operated services, whether communtiy services or developmental center.

In addition, I would like to obtain a copy of the OMR/DD Policy Manual.

Please advise me if there are costs involved before sending me the requested information. Thank you for your cooperation.

Sincerely,

Stephen J. Taylor

Stephen J. Taylor, Ph.D.

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Printed by Sheltered Occupational Center of Northern Virginia

Mental Health Law Project

Sponsored by American Civil Liberties Union Foundation, American Orthopsychiatric Association and Center for Law and Social Policy

Suite 300
1220 Nineteenth Street NW
Washington DC 20036
(202) 467-5730

November 14, 1979

Mr. David Snight
Contracts Office
National Institute of Mental Health
Room 11-A-10
5600 Fishers Lane
Rockville, Maryland 20857

Dear Mr. Snight:

Under the provisions of the Freedom of Information Act, I hereby request a list of all persons and organizations who submitted proposals pursuant to RFP No. NIMH-MH-79-0046, entitled "Demonstration Program to Evaluate Models of Advocacy Programs for the Mentally Ill and the Developmentally Disabled." In addition to the name of each organization or individual, please include the address, phone number, and whether a contract was awarded.

If there is a charge for reproducing these materials, please let me know.

Thank you.

Sincerely,

Leslie J. Scallet

LJS:vjh

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State Plans

States must submit comprehensive plans to the federal government to receive certain forms of federal financial assistance. These plans are useful in identifying state priorities and showing how a state intends to use federal funds. The following state plans are the most important for monitoring services for people with developmental disabilities:

* DD (Developmental Disabilities) Plan, required for states to receive federal funds under the DD Assistance and Bill of Rights Act. (Contact your state developmental disabilities council or your regional office of the U.S. Department of Health and Human Services -- HHS.) 1/

* Title XIX Medicaid Plan. (Contact your state department of health or the regional office of HHS.)

* Title XX Social Security Act Plan, which should contain provisions for follow-up services for deinstitutionalized persons. (Contact your state department of social services or public welfare or the regional office of HHS.)

* PL 94-142 Plan, which should contain assurances that all handicapped children, including those in institutions, are provided with a free public education. (Contact your state department of education or the regional office of the federal Department of Education -- E.D.)

* Vocational Rehabilitation Plan, required for states to receive federal funds for rehabilitation services under the Rehabilitation Act of 1973 (and its amendments of 1974, 1976 and 1978). (Contact your state department of vocational rehabilitation or the regional office of the E.D.)

The state DD Plan will be most useful for monitoring your state's institutions and deinstitutionalization efforts. Federal law requires DD plans to include the following kinds of information, among others (42 U.S.C. §§ 6001-6081):

* state objectives and a listing of programs and resources to be used to meet the objectives;

* services to be provided to persons with developmental disabilities under other federally assisted state programs related to education, vocational rehabilitation, public assistance, health, medical assistance, social services, maternal and child health, mental health and others;

1/ A listing of the regional offices appears later in this chapter.

* a method for periodically evaluating the plan's effectiveness;

* provisions for the development, review and revision of a comprehensive statewide plan to plan, financially support, coordinate and otherwise better address unmet needs in the state for at least one area of priority services; (The four federal priority services are case management, child development services, alternative community living arrangements and nonvocational social-development services)

* provisions that services are provided in an individualized manner consistent with the standards for individual habilitation plans (IHPs);

* the state's plan for eliminating inappropriate placements in institutions and for improving the quality of care of persons in institutions;

* data on the numbers of people who are developmentally disabled.

Medicaid Reports

Under Title XIX Medicaid, residential facilities for the developmentally disabled are eligible to receive federal funds for ICF/MRs or ICF/DDs ("Intermediate Care Facilities for the Mentally Retarded" or "Developmentally Disabled"). Title XIX funds may be used to support small, community-based settings. However, in most states Title XIX monies are used almost exclusively to fund institutions.

As a condition of receiving Title XIX funds, a residential facility must submit to periodic inspections according to ICF/MR or ICF/DD standards, usually conducted by the state health department. After the inspection, the facility is provided with a "deficiency report" -- a list of specific deficiencies found there. The facility must respond to each deficiency with a plan and date for correction.

You have a right to obtain copies of Medicaid deficiency reports. Write the regional office of HHS to request copies of these reports. Be sure to offer to pay duplication costs. The average report runs about 20 pages. If you are unfamiliar with the Medicaid standards themselves, you should also request a copy of these.

The deficiency report will contain for each deficiency the number of the relevant standard, a brief description of the deficiency and where it was found, the facility's plan of correction and the date by which the deficiency will be corrected. Deficiency reports and inspection procedures vary greatly by state. In most states, the reports focus on bureaucratic standards (for example, the amount of space in a sleeping area or the adequacy of written policies) as opposed to the quality of life at the facility. Further, Medicaid officials sometimes accept vague promises to correct a deficiency rather than requiring specific plans of correction; they may grant repeated extensions for facilities to meet the standards.

Some states have not applied for Medicaid monies, knowing that their facilities could never even come close to meeting the standards. In these states, of course, you will not be able to obtain Medicaid inspection reports.

Regional Offices: Department of Health and Human Services

Region 1

(Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont)
Regional Director's Office
John F. Kennedy Federal Bldg.
Boston, MA 02203
(617) 223-6830
(8) 223-5746-FTS */

Region 2

(New York, New Jersey, Puerto Rico, the Virgin Islands)
Regional Director's Office
26 Federal Plaza, Rm 3838
New York, NY 10007
(212) 264-4600
(8) 264-5736-FTS */

Region 3

(Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, West Virginia)
Regional Director's Office
3535 Market St.
Philadelphia, PA 19101
(215) 596-6492
(8) 596-1224-FTS */

Region 4

(Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee)
Regional Director's Office
101 Marietta St.
Atlanta, GA 30323
(404) 221-2442
(8) 242-2089-FTS */

Region 5

(Illinois, Indiana, Minnesota, Michigan, Ohio, Wisconsin)
Regional Director's Office
300 South Wacker Dr.
Chicago, IL 60606
(312) 353-5160
(8) 353-8416-FTS */

Region 6

(Arkansas, Louisiana, New Mexico, Oklahoma, Texas)
Regional Director's Office
1200 Main Tower Bldg.
Dallas, TX 75202
(214) 767-3301
(8) 729-2961 or 2958-FTS */

Region 7

(Iowa, Kansas, Missouri, Nebraska)
Regional Director's Office
601 East 12th St.
Kansas City, MO 64106
(816) 374-2821
(8) 758-5211-FTS */

Region 8

(Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming)
Regional Director's Office
1961 Stout St.
Denver, CO 80294
(303) 873-3373
(8) 327-4106-FTS */

Region 9

(Arizona, California, Hawaii, Nevada, Guam, American Samoa, Wake Island, Trust Territories of the Pacific Islands)
Regional Director's Office
50 United Nations Plaza, Rm. 483
San Francisco, CA 94102
(415) 556-6746
(8) 556-7774-FTS */

Region 10

(Alaska, Idaho, Oregon, Washington)
Regional Director's Office
Arcade Plaza Bldg., Rm. 615
1321 Second Ave. (MS 622)
Seattle, WA 98101
(206) 442-0420
(8) 399-5462 or 5314-FTS */

*/ Toll-free line of the developmental disabilities protection and advocacy agency.

Service System Data

Most state agencies responsible for providing institutional and other services for the developmentally disabled population collect a wide range of statistical data and other information and develop policy and procedure manuals. This information should be accessible to the public. Sometimes agencies maintain lists of reports, documents and materials that are available to the public and issue procedures for obtaining this information. Check to see if your state agency maintains such lists before requesting public information.

States vary widely in the kinds of information collected by public agencies. However, most state agencies gather the following forms of information:

* number of public institutions and state-certified community residences;
* census data on the number of people in institutions, community residences, foster family care and other arrangements, broken down by age, type of disability, sex, race and level of retardation;
* expenditures for institutions and community services;
* programming provided to residents of institutions and community residences, broken down by program (e.g., education, physical therapy, occupational therapy, vocational rehabilitation, etc.) and resident characteristics (i.e., type of disability, age, race, sex and level of retardation);
* operating procedures, policies and, for privately operated services, certification standards;
* staffing figures broken down by type of staff (e.g., administrative, clerical, professional, direct-care, janitorial, etc.);
* tabulations of death rates and incidents (e.g., accidents, injuries, runaways, etc.).

Of course, it's wise to assume, when reviewing this kind of information, that it paints the most positive picture of the state's institutional and community services. In particular, programming data are likely to overestimate the number of people receiving actual programming.

CHAPTER III. MONITORING

The most effective way to monitor residential settings is to visit and observe them yourself. By being there, you let administrators and staff know that they are accountable for the services provided to residents. Generally speaking, the more outside visitors to a facility, the better the conditions and care received by the people who live there.

You should also try to record what you see and hear on such a visit. By recording your observations, you build a record for media coverage, action reports, legislative testimony, negotiations and other strategies.

This chapter describes two approaches to observing residential facilities and recording information: the checklist approach and descriptive reports. Your choice will depend on your own time and resources, your access to experienced observers and the sophistication of the members of your group.

Access

To monitor a residential facility, you must have access to it. Usually you can gain access simply by requesting it from top officials. If you just want to get a general impression of the facility, you can accompany parents or family members on visits. No facility can deny entry to family members and others of their choosing.

Sometimes you will have to negotiate for access to an institution or community facility. Legitimate consumer, professional and advocacy organizations, especially protection and advocacy agencies, have a right to enter public facilities and to be informed of what occurs in these organizations. Your success in gaining access will almost always depend on your determination.

Do not be afraid to threaten publicity or even legal action if you are denied access to a public setting. Agency officials know that they will appear to be trying to hide something if they keep you out. Most would rather let you in than risk the appearance of a cover-up. Some groups have successfully used the tactic of showing up at an institution with TV reporters when attempts to gain access amicably have failed.

You should be prepared to make certain guarantees when entering a facility: not to disrupt routines or ongoing activities; to check in with the administration before visiting living units or program areas; to respect the privacy and confidentiality of residents; to limit the number of people visiting at any one time. You do not, of course, have the right to review individual residents' records unless you have their permission or that of their guardians.

Gaining Access to Institutions: An Example

A Center on Human Policy organizer managed to have the state reverse a policy denying access to an institution. First, the organizer wrote a series of registered letters to the institution director and to the mental health commissioner, demanding the right of access and the right to know what occurs inside the public institution. Each letter suggested that if a positive answer was not forthcoming, legal action would follow. When the letters produced no immediate solution, the organizer and a public-interest attorney went to the institution to meet directly with its director. The advocates demanded the right for all advocacy groups to know about institutional life and to have regular access to the institution. When the institutional director agreed to these conditions, the attorney prepared a contract to be signed by the organizer and by the institution director. The attorney then negotiated with state officials to have the language of the agreement incorporated in regulations as state policy.

MODEL AGREEMENT

October 27, 1972

The following agreement results from a meeting held at a State Hospital on October 11, 1972. Those present at such meeting were Dr. James and Dr. Martin, Director and Assistant Director, respectively, of the State Hospital and Douglas Biklen from the Center on Human Policy at Syracuse University, Carole Hayes from the Mental Patients Liberation Project in Syracuse and John Kennedy from the Legal Services-Health and Nutritional Development Project in Rochester.

On behalf of the State Hospital, and as its director, Dr. James hereby agrees that:

(1) Members and representatives of the Center on Human Policy, the Mental Patients Liberation Project in Syracuse and the Legal Services-Health and Nutritional Development Project will have access into the State Hospital with the right to visit patient residential areas and all patient program areas, including but not limited to schools, recreational facilities, rehabilitation facilities, occupational therapy facilities, physical therapy facilities, industrial workshops and eating facilities.
(2) Such visitors from these three groups will be allowed to talk privately with patients and staff.
(3) Such visits may be conducted at any time, day or night.
(4) Such visits may be made without the supervision or presence of hospital staff or personnel.
(5) Staff personnel will assist such visitors in unlocking doors when requested.

On behalf of the Center on Human Policy, the Mental Patients Liberation Project and the Legal Services-Health Nutritional Development Project, Douglas Biklen, Carole Hayes and John Kennedy hereby agree that:

(1) Such visits by members or representatives of their groups will be conducted in a professional manner and only for the purpose of advocating for the rights of patients.
(2) Such visits will not unduly disrupt or interfere with patients' sleeping, patients' eating, programs in session or staff duties.
(3) No more than two (2) persons from all three groups combined will make visits at the same time.
(4) Visiting persons will properly identify themselves to the supervising staff and personnel upon arriving at any given building.
(5) These three groups will bring to the attention of Dr. James' office any major complaints that result from such visits prior to taking any other action.

_____
Edward James, M.D.
Director, State Hospital

_____
Douglas Biklen

_____
Carole Hayes

_____
John Kennedy

The Checklist Approach

When you visit an institution or community setting, an observational checklist is a simple and efficient way to monitor. Checklists yield basic data on physical settings, population characteristics, staffing, the use of restraints and general living conditions.

The checklist approach is not only a monitoring device; it's also an organizing tool. Checklists raise people's consciousness about conditions at a facility and get them actively involved in scrutinizing the quality of care provided to residents.

Checklists should be as simple and straightforward as possible. They should be designed so that parents, volunteers and others can complete them during regular visits to facilities.

Be sure to instruct people where to send their checklists after they have completed them.

When using a checklist, try to follow these guidelines:

* Familiarize yourself with the checklist before you make your visit. This will help focus your attention on important details.

* Be unobtrusive. Conspicuous checking against a list can intimidate staff and lead them to alter normal practices. If possible, try to record your observations in private or after you have left the facility.

* Force yourself to concentrate on everything you see or hear happening. You will be surprised at how much you can remember about your visit.

* Complete the checklist as soon as possible after your visit.

* Do not record staff members' or residents' names on the observation checklist. This serves no purpose and may violate someone's confidentiality. Of course, if you see someone engaging in an illegal or inappropriate activity, you should report it to a responsible official.

* Any time you are unsure what to check on the form, write down your comments. It's better not to check anything than to check misleading items.

* Be as complete as possible. For example, don't hesitate to record something negative just because you observe many positive things in the setting. Positive and negative observations do not cancel each other. One violation of rights is one too many!

* Be descriptive. For instance, instead of "nothing was happening," record observations like the following: "About 15 residents were sitting in the dayroom. Several were sleeping. Two were rocking back and forth in their chairs. The rest were watching TV or sitting quietly. Five were standing or wandering around the dayroom. One was saying 'Hey!' to get the attendant's attention, but he was ignored. Two attendants were in the dormitory folding laundry; the other was watching TV in the dayroom."

* Try to think how you would feel if you lived in the setting. For example, when observing a meal, ask yourself: Do residents have enough time to eat? Does the food look appetizing? Is it handled by staff in an appetizing manner? Is the food served family style? Do residents have to line up to receive their meals? Are there napkins? By putting yourself in the residents' shoes, you will notice things you might otherwise take for granted.

* Fill in a checklist after every visit. Of course, you can skip those things that haven't changed, but note those that have.

Information gathered through checklists can be used in a variety of ways: to help your group select priorities for your advocacy efforts, to identify conditions or practices which need to be changed immediately, to challenge official data or statistics, to prepare a report on services in your state or community. See Chapter VII for a discussion of advocacy strategies that can be used along with monitoring activities.

SAMPLE OBSERVATIONAL CHECKLIST

When complete, send or take to (name of advocate/organization).

YOUR NAME _____

I. BACKGROUND INFORMATION

1. Facility name and location _____
2. Unit (ward) _____
3. Date of visit _____ Day of the week _____
4. Times of observation _____

II. POPULATION

5. Number of residents living on unit _____
6. Sex of residents: Male _____ Female _____ Mixed _____
7. Age of residents:

   Children (0-12) _____

   Adolescents/teenagers (13-20) _____

   Young adults (21-35) _____

   Adults (36-54) _____

   Older adults (55 and up) _____
8. Physical Disabilities:

   Ambulatory _____

   Nonambulatory _____

   Mixed (specify numbers) _____
9. Level of retardation (as described by staff):

   Mild _____ Moderate _____

   Severe _____ Profound _____

Comments: _____

III. STAFFING

10. Number of direct care staff assigned to unit:

Total _____ Morning/early afternoon _____

Late afternoon/evening _____

Night _____

11. Number of direct care staff on unit during visit _____

12. Number of supervisors on unit during visit _____

13. Number of professional staff (e.g., teachers, physical therapists) on unit during visit _____

14. Number of volunteers on unit during visit _____

Comments: _____

IV. PHYSICAL ENVIRONMENT

15. Rooms (check if they exist and specify number):

Dayroom/living room _____

Sleeping areas:

Dormitories _____ with _____ beds in each

Private or semi-private rooms _____

Partitioned dormitories _____ with _____ beds in each

Dining areas _____

If no dining area on unit, where do residents eat? _____

_____

Bathrooms _____

16. Cleanliness:

In general, was the unit clean or dirty? _____

Did you notice any offensive smells? _____

Comments: _____

_____

17. Locks and barriers:

Was the living unit locked? _____

Were areas within the unit locked? _____

Were the windows barred or reinforced with wire mesh? _____

_____

Comment: _____

18. Isolation ("time-out") rooms:

Were there any isolation rooms on the unit? _____

Were they being used? _____

Comment: _____

19. Decorations and furnishings:

Dayroom/living room:

Homelike _____

Barren _____

Somewhat decorated _____

Comment: _____

_____

Sleeping areas:

Homelike _____

Barren _____

Somewhat decorated _____

Do residents have dressers and places to store their clothes and personal possessions? _____

Comment: _____

_____

Dining areas:

Homelike _____

Barren _____

Somewhat decorated _____

Comment: _____

_____

Bathrooms:

Do the bathrooms afford privacy for residents? _____

Do the toilets have stalls? _____

Do the toilets have seats? _____

Do the bathrooms have the following:

Toilet paper _____

Soap _____

Towels _____

Mirrors _____

Comment: _____

_____

Additional comments on the physical environment: _____

_____

V. CLOTHING AND PERSONAL APPEARANCE

20. Clothing:

Were all the residents fully clothed (including shoes and socks)?

_____

Were all the residents dressed in stylish and suitable clothing?

_____

21. Personal appearance:

Did the residents have a normal appearance for their sex and age (e.g., hair, shave, etc.)? _____

Did the residents have many bruises, cuts or scars? _____

_____

Comments on clothing and personal appearance: _____

_____

_____

VI. RESTRAINTS

22. Were any residents in straitjackets? _____

23. Were any residents tied in any way? _____

24. Were any residents wearing helmets? _____

25. Were any residents wearing coverings over their hands? _____

_____

26. Were any residents placed in totally enclosed cribs? _____

27. Were any residents restrained in any other way? How? _____

_____

Comments: _____

_____

_____

VII. STAFF ACTIVITIES

28. What were staff members doing during your visit? (Be as descriptive as possible and be sure to include whether they were involved in programming with residents.) _____

_____

_____

_____

29. Were staff members interacting with residents? How did they interact with them (e.g., casual conversation, harsh commands, teasing, etc.)?

_____

_____

_____

_____

VIII. RESIDENT ACTIVITIES

30. How many residents were on the unit during your visit? _____

31. If some residents were off the unit, where were they? _____

_____

_____

32. What were the residents doing during your visit? (Be as descriptive as possible and be sure to note whether any structured activity was occurring on the unit.) _____

_____

_____

_____

_____

_____

33. ON UNITS FOR NONAMBULATORY RESIDENTS: Were the residents in bed during normal waking hours? Were any residents lying on the floor? Did residents appear to be positioned in any special way? Did wheelchairs appear to be individually fitted? _____

_____

_____

_____

_____

IX. GENERAL COMMENTS ON VISIT (Use back of page if necessary.)

Descriptive Reports

Descriptive reports are based on careful observation and detailed description of the conditions and practices at residential settings. They are usually prepared by experienced observers or experts in the field of developmental disabilities. With some practice in observation and recording and some writing skills, however, almost anyone can prepare a descriptive report on an institution or community residence.

If you do need assistance in preparing this kind of report, you might see if someone on the faculty of your local university has experience in observing residential facilities. One of the following national groups may also be able to provide you with on-site consultation or help you identify experts in your region of the country: Center on Human Policy (216 Ostrom Ave., Syracuse NY 13210), Mental Health Law Project (Suite 300, 1220 Nineteenth St. NW, Washington DC 20036), National Association for Retarded Citizens (2709 Avenue E East, Arlington TX 76011) or the Public Interest Law Center of Philadelphia (1315 Walnut St., 16th Floor, Philadelphia PA 19107).

Descriptive reports are not intended to yield an "objective" overall view of a facility, if "objective" means devoting equal attention to both positive and negative aspects. As a monitoring strategy, descriptive reports should be oriented to violations of legal and moral rights -- things that are seldom reported and that need to be changed. Given this orientation, the observer should report his or her observations as honestly, completely and objectively as possible.

To write a descriptive report, you will need to know how to tour a facility. In general, people attempt to present themselves in the best possible light in

the presence of strangers. It is only natural that facility staff will react to observers in this manner. They will show those aspects of the setting in which they are seen in a favorable light and hide, or at least downplay, aspects in which they know deficiencies exist. Institutional officials often show visitors the best wards and model programs, for example, and discourage visitors from looking at other parts of the institution.

It is therefore important that you select the places and times to observe. Prior to the tour, try to find out as much as possible about individual units within the setting. When you visit an institution, ask for a map of the grounds and buildings. This will give you a frame of reference for the tour and let you decide which buildings or living units you want to visit.

Here are some general guidelines on deciding which units to tour:

* Visiting residential units tells you more about a facility than visiting program areas. After all, residents spend more of their time in the residential reas. However, finding a program area empty and equipment unused can be very indicative about what actually occurs at the facility.

* You will usually observe the most blatant violations of rights in units for people labeled "nonambulatory," "severely and profoundly retarded" and "behavior problems." These units are typically located farthest from the facility administration building.

* Unless you want to alienate the officials, do not refuse to visit the token model programs or the "special event" (e.g., the carnival or dance). Of course, do not spend all of your time there.

Participant observation is a sociological technique for studying social settings.[2/] You can use a modified version of this technique for conducting your

2/ For further reading, see Robert Bogdan and Steven J. Taylor, Introduction to Qualitative Research Methods. New York: John Wiley, 1975; and Joseph Ferreira and Bill Burges, Collecting Evidence: A Layman's Guide to Participant Observation. Boston: Institute for Responsive Education, 1975.

observations at residential facilities. Participant observation involves, first, trying to blend into the setting by acting unobtrusively; second, concentrating intensely on what you see and hear, third, writing up field notes after you have left the setting; and fourth, putting together a descriptive report.

Experienced observers usually take several days to write a report based on one day's observations. Institutional tours can be extremely draining psychologically, emotionally and physically.

Here are some suggestions for observing residential facilities and writing descriptive reports:

* Try to act as unobtrusively and naturally as possible.

* Concentrate on what you see and hear. When you first enter a unit, stop, look around and form a mental picture of what you see.

* When speaking with staff, identify "key words" in the conversation -- words that will enable you to reconstruct the conversation later (e.g., "drugs," "troublemakers," "restraints").

* Observe as much of each living unit as possible. Wander casually around the unit. Check bathrooms (see if there are toilet stalls, toilet seats, toilet paper, soap and towels), dormitories and other rooms. Ask to see the isolation or "time-out" room if there is one.

* Try to get staff members to talk without giving away your perspective. Ask a lot of "why," "how come" and "what's it like here" questions. For example, if you see residents naked, restrained or locked up, ask why. You might be able to predict the answers (e.g., "Oh, he's hyperactive and bothers the other residents."), but you want staff to put it in their own words. Don't ask threatening questions or challenge staff. This will only encourage them to "clam up" or feed you the "official line."

* Record only as many notes as necessary to jog your memory when you write up your observations: the building or unit, the number of residents and staff and a few words that will enable you to reconstruct a mental picture.

* Take a pocket-size notebook on the tour with you. Jot down your notes outside of the living unit and, if possible, in private.

* Be careful not to be seduced by institutional language or rationales. Take nothing for granted. For example, staff may refer to an isolation cell as a "time-out room," defining a control measure as a therapeutic technique. Or you may be informed that a resident prefers being in isolation or locked in a room alone. Unless you are skeptical of language and rationales, you may fail to note that and you will thus miss an important aspect of the setting.

* After you have left the facility, record your observations in the form of narrative field notes. Your field notes should contain concrete descriptions, not vague impressions, and as many quotations as possible. Your ability to recall what you saw and heard will be enhanced if you write up your field notes on the same day you conducted your observations.

* Include on your report specific descriptions of settings and people and plenty of quotations from your notes. The report should also educate the reader as to why conditions you observed should not exist.

Descriptive reports can also be based on a team-observation approach.[3/] A team approach requires planning and coordination. Observers should receive training in the nature of institutions, ethical issues (e.g., confidentiality), unobtrusive observation skills and writing up of field notes. At the facility, observers should be assigned to individual buildings or units for the duration of the visit. Each person should observe for periods of one to three hours. Arrangements should be made to have a private room set aside for observers to record field notes between observation sessions.

After several visits to the same unit, observers are generally surprised at the candor and openness of staff. (You might want to guarantee the confidentiality of individual staff members.) For example, staff typically complain about supervisors and professionals at the facility and admit to violating facility policies. Observers may even witness instances of physical and psychological abuse at institutions.

3/ See Douglas Biklen, Human Report 1. Souls in Extremis. Burton Blatt (ed). Boston: Allyn and Bacon, 1973; Steven J. Taylor, Douglas Biklen, and Robert Bogdan, An Evaluation of Empire State School. Syracuse: Center on Human Policy, 1975; and Steven J. Taylor. A Working Paper on the Quality of Life and Nature of Institutionalization at Belchertown State School. Syracuse: Center on Human Policy, 1976.

The success of a team-observation approach depends on the observers' recording detailed, accurate and clear field notes. The field notes can be photocopied and then cut up and sorted into categories corresponding to sections of the descriptive report. A sample outline for the report follows:

I. Staff Reactions to the Observers

II. Quality of Life

Physical Environment

Daily Routines - Meals, Bathroom Routines, Sleeping Routines

Clothing and Personal Appearance

Staff Language and Definitions of Residents

Control Measures - Punishment, Isolation, Restraints, Drugging, Abuse

III. The Staff

Staffing Ratios

Recruitment

Training

Staff Communication

IV. Programming

Ward Activities

Off-the-Ward Programs

Medical Care and Facilities

Volunteers

V. Conclusions and Recommendations - From Institution to Community

The appendix to this manual contains the full text of a descriptive report based on the author's observations at two North Dakota institutions. The following section summarizes another.

Descriptive Reports: An Example

In the spring and summer of 1979, the Human Rights Committee of Lincoln (Nebraska) Regional Center conducted an investigation of alleged human rights violations on one unit of that institution. The investigation resulted in the public release of a descriptive report entitled, "An Investigation into Allegations of Human Rights Violations at the Lincoln Regional Center Comprehensive Care Unit, 2-East," authored by John McGee, Ph.D.

The Lincoln Regional Center report included seven pages containing the findings and recommendations of the Human Rights Committee as well as a detailed appendix containing Dr. McGee's observation notes. After a brief introduction and description of the unit, the report listed a set of specific findings:

> We found a series of basic weaknesses in the program, each of which contributes to human rights violations. The sum total of these weaknesses has inevitably resulted in what can only be described as bedlam. We found:
>
> 1. Cruel and unusual punishment in the place of behavioral management
>
> 2. Nearly total programmatic emptiness rather than developmental programs
>
> 3. Paper compliance with standards in place of strong, direct administrative leadership demanding excellence in service
>
> 4. Unsanitary conditions
>
> 5. Racism
>
> These flaws, when combined, leave the residents in a grossly inhumane setting. These systemic flaws have apparently existed for some time. They definitely have arisen due to a general lack of leadership at the highest levels of DPI administration, for it is virtually impossible for such obvious and grossly inhumane conditions to exist without either the knowledge or the neglect of the institution's administration.

The report elaborated on each of these specific findings and included numerous examples of human rights violations.

The concluding section of the McGee report stated the Human Rights Committee's recommendations:

1. To completely eliminate the reign of punishment on the Unit.

2. To immediately develop for the residents of 2-East a program of services based on the developmental model, structured sufficiently enough to afford the residents of training in self-care skills, interpersonal skills, communication skills, etc.

3. To immediately embark on an intensive training program for line staff in the developmental model, appropriate behavioral management and the human and legal rights of the residents.

4. To ensure that the Human Rights Committee is able to function in the best interests of the residents.

The report's appendix contained 14 pages of detailed description of Dr. McGee's 17 hours of observation on the unit, providing documentation for the McGee report's findings and conclusions. The following are excerpts of Dr. McGee's recorded observations on the "comprehensive care unit."

> 2:10 - An adult female was seen in an unwatched time-out room. Her wrists and hands were tied with leather restraints. She sat quietly on the bare floor. She was completely naked. (5/14/79)
>
> 2:15 - There were more than 20 residents on the ward. The general scenario was one of bedlam. The woman was still in the time-out room. Various men and women were roaming the corridors, some half-clothed. As I walked around, I saw one man on top of another man masturbating. Several other men were in their beds masturbating. I saw absolutely no staff interaction with the clients at the time. (5/14/79)
>
> 8:00 P.M. - We entered the ward again. Bedlam had returned. As we entered the corridor, I saw: one man in pajama tops, one woman in a hospital gown to her waist, two residents in their clothes, three men in open robes, the rest of the men and women were wandering the hallways in various stages of nudity. As this was happening, I saw two female staff bathing two men and a male staff member shower-

> ing a woman. The other two staff persons were reading newspapers. I later discovered a nurse spends most of her time hidden in an enclosed nurses' station, completely out of sight. Both of the persons who earlier had been in restraints in the time-out room were wandering the corridors aimlessly. Eventually the nurse started to appear with bed-time medication. As we were leaving, we saw one staff attendant reading a book, two or three attendants in the glass-enclosed office, two attendants at the exit (one reading a newspaper and one doing a crossword puzzle), and one attendant working (picking up garbage.) (5/14/79)
>
> 9:25 - I observed a male resident in the same room still in bed. Another resident was in the hall walking in circles. In the day room, two attendants were smoking. A resident sat alone. Nearby a male resident was lying on the floor. As I walked out of the day room, I saw yet another resident in bed asleep. (5/17/79)
>
> 11:45 - We entered the ward. We saw one resident sitting on the hallway floor, half asleep. Another resident was becoming upset. Staff appeared not to heed these signs. A few minutes later the resident began to scream. A staff person shouted at the resident: "This is not funny...not appropriate..." He then picked up the resident's shoes and threw them on the floor. The resident was then taken to the Day Room, placed in restraints and remained there with a staff person. (5/19/79)

Note that the observation notes record the time and contain careful description and, where appropriate, quotations.

The McGee report was presented to Nebraska officials and released publicly at a press conference called by the Nebraska and Capital Associations for Retarded Citizens.

This chapter has dealt with two direct-observation approaches to monitoring residential settings. The following chapter turns to a closely related strategy of monitoring institutions and community settings -- sponsoring or calling for professional investigations.

CHAPTER IV. INVESTIGATIONS

Scandals -- suspicious deaths, scaldings, abuse -- are common at institutions. They also occur, though to a far lesser extent, in community residences. An important monitoring role of advocacy groups is drawing attention to abusive events and conditions -- in effect, exposing a scandal -- by demanding or sponsoring independent professional investigations.

Professional investigations are usually called for in the following situations:

* When advocacy groups have indirect knowledge of abusive conditions at a facility, but have been denied access to visit or otherwise obtain direct information about it;
* When advocacy groups have been unsuccessful in drawing attention to abusive conditions through other means; or
* When a thorough understanding or review of a situation requires professional expertise.

Of course, when public officials already admit deficiencies or when deficiencies have already been thoroughly exposed or documented, there's no point in yet another investigation. That's the time to take action.

Professional investigations are most effectively used to review circumstances surrounding a specific case or set of related cases -- suspicious deaths, for example. If your group has high visibility and a reputation for action in your community, parents, facility staff and other "whistleblowers" probably bring a number of abuse cases to your attention. Your first task is to decide which warrant formal investigation. Here are some considerations.

* You should be able to verify at least some of the factual circumstances surrounding the case. This is where staff insiders -- otherwise unable to act without risking their positions -- become invaluable.

* You have alerted the residents involved and their guardians that you intend to call for an investigation and have attempted to gain their support, or at least their passive approval.

* The case should involve systemic issues; it should dramatize the situation of a significant number of persons. Premature death and similar events are usually rooted in systemic causes -- a pattern of inadequate care. By investigating a single case, you identify conditions affecting all people at a facility. But some cases stem from individual causes. For example, a case would probably not be worth investigating if it involved wrongdoing on the part of a single staff member, but would be if it represented failure of officials to take proper action or to supervise staff members generally.

* Investigation should not jeopardize the interests of the larger group of which the abused individual is a part. For instance an investigation of criminal acts by a former institutional resident could result in community backlash against deinstitutionalization.

You will also need to decide whether you want to sponsor your own investigation -- recruiting professionals, setting up the panel and obtaining access to necessary information -- or demand that public officials appoint an independent review panel. If you select the latter course of action, be alert to the possibility of a "whitewash." Do not give your approval to any investigation panel that is not composed of truly independent persons. You should also demand that the findings of any such investigation be available to the public.

Requesting an investigation through private communications with public officials is not worth much. You should be prepared to make such a demand pubicly through the media. Even if officials refuse to cooperate, your public call for an investigation will place pressure on the system to change.

Professional Investigations: An Example

Lori W. was a 12-year-old multiply disabled resident of a new, medium-size state institution.[4/] In January 1976, Lori W. died suddenly of pneumonia. One

4/ See Special Report: Independent Review of Circumstances Surrounding the Death of Lori W. at Syracuse Developmental Center. Syracuse: Center on Human Policy, May 1976.

staff member at the institution, who was familiar with practices at the facility generally and on Lori's unit specifically, believed that Lori's death might have been prevented. She contacted an advocacy agency, suggesting that someone look into the situation.

An organizer from the advocacy group met with the staff member to obtain additional information concerning Lori's death. The staff member indicated that staff on Lori's unit may have been inadequately trained to deal with Lori's medical and physical needs. Additionally, she said, unit staff offered conflicting accounts of the events leading up to Lori's death. The organizer asked institutional officials for additional information. Officials confirmed that Lori had died suddenly, but added that sudden deaths are not uncommon among multiply disabled persons.

The organizer next contacted Lori's parents. He explained that a staff member at the facility questioned Lori's death. Lori's parents said they had been dissatisfied with the quality of care provided to her and noted that in the period preceding her death she had been suffering from congestion, among other conditions. The parents offered their support and willingness to cooperate with an independent investigation.

Representatives from five local parent and consumer organizations were called together to discuss Lori's death. They agreed to sponsor an independent review of the situation. At subsequent meetings, they selected seven persons to serve on the review panel: two out-of-town physicians -- one a well-known pediatrician with experience at institutions and one an internist and parent of a severely physically disabled child; two registered nurses, both parents of developmentally disabled children; a sociologist experienced with institutions; a human services administrator; and a parent of an adult at the institution. A local pediatrician was recruited to provide consultation to the panel.

The five-group coalition held a joint press conference to announce their intention of sponsoring a professional review of Lori's death. At first, institutional and state officials agreed to cooperate with the investigation, but later they stated they were unwilling to cooperate. However, finally, in front of TV cameras, they again agreed to cooperate. Officials also announced that they had conducted an internal investigation of Lori's death. Their conclusion: No staff member was negligent in caring for Lori.

The review panel went beyond considerations of individual staff negligence to examine the general pattern of care provided to Lori. Panel members interviewed more than 20 persons, including staff members on the unit and Lori's parents, and reviewed hundreds of pages of records, administrative policies and reports. After three months of investigation, the review panel issued its final report.

The panel concluded that although no individual staff member was negligent, it was "highly probable" that Lori's death could have been prevented. The panel noted that she required intensive care and treatment, which was not provided. Among the panel's major findings were the following:

* Staff were not prepared and trained in preventative medical management, potential warning signs, recognition of critical illness, basic first aid, the use of emergency equipment and the execution of emergency procedures. Lori had been ill on the day she died; yet staff members, unaware of the potential seriousness of her illness, took no action to treat her or have her seen by a physician.

* Lori's care was fragmented and discontinuous. Ironically, she received good medical, physical-therapy and other evaluations at the facility, with appropriate recommendations for care and programming. The problem was that none of the recommendations were implemented.

* Lori received regular dosages of Valium and phenobarbital, with little or no monitoring for adverse side effects. Valium, used in conjunction with phenobarbitol, can cause changes in saliva (among other side effects), thereby increasing congestion and, indirectly, leading to pneumonia.

The review panel located the cause of Lori's death in administrative and management deficiencies. The panel made six specific recommendations regarding internal administrative procedures at the facility and a general recommendation to expand community-based services for severly disabled persons.

The panel's recommendations and conclusions were announced at a press conference held by panel members. The story was reported by area TV and radio stations and on the front pages of area newspapers. The panel's 25-page report was also forwarded to the governor, state officials and relevant legislative committees.

Professional Investigations -- Access Denied

In the winter of 1975, four residents of Rome Developmental Center, a large old public institution, died during a single weekend. The following week, a team of staff from another state institution visited Rome to evaluate specific residents who were scheduled for transfer to the other facility. The team was shocked by what it found at Rome -- inadequate conditions overall as well as a flu epidemic in the children's building. The team members later stated that the children were not being appropriately treated for the flu -- no quarantine measures had been adopted and there was a shortage of medical staff. They were also informed by Rome staff that the four residents had died during the preceding weekend. Two children had died from flu; a third had choked to death on a peanut butter sandwich (choking is a leading cause of death at state institutions and is often attributable to institutional conditions and practices). An older resident had died of "natural causes."

As soon as they returned to their own facility, the team members called an advocacy group and urged that something be done about the deplorable conditions at Rome. The advocacy group's first step was to contact Rome's director,

who confirmed that four residents had died during a single weekend and that there was a flu epidemic in the children's building.

The advocacy group called a meeting of eight area consumer and advocacy organizations. The organizations agreed to form a coalition to demand an investigation of the Rome deaths. The following telegram, signed by the eight groups was sent to the governor, the state commissioner and the director of the institution:

> It has come to our attention that a critical condition exists at the Rome Developmental Center which may be potentially life threatening.
>
> Several children and at least one adult died at Rome within a period of 36 hours, under questionable conditions.
>
> Your immediate attention is demanded in safeguarding the other residents in your care. A licensed physician should be called into attendance immediately.
>
> Attention is demanded in order to prevent any additional deaths.

Coalition representatives, accompanied by TV reporters, toured Rome Developmental Center the following day. Conditions at Rome were publicly exposed for the first time since Robert Kennedy's publicized visit there in 1965. (Kennedy commented on his trip to Rome: "I was shocked and saddened by what I saw there....There are children slipping into blankness and lifelong dependence.") At a press conference the same day, the coalition reiterated its demands for an independent investigation of the Rome deaths.

State officials initially announced their intention of investigating Rome conditions and the deaths. Later, however they stated that an investigation was unwarranted.

The coalition enlisted the support of statewide groups. The state Association for Retarded Children and a statewide federation of parent groups sent telegrams to the governor demanding a full-scale investigation. The state chapter of the American Association on Mental Deficiency (AAMD) said it would form an independent review panel to investigate the deaths.

The state announced that it would not cooperate with the AAMD investigation. No records would be provided; no staff would be available to be interviewed. Because the identity of the residents' parents or guardians was unknown, their support for an investigation could not be obtained. Thus, by "stonewalling," the state successfully thwarted an independent review of the deaths.

Were the demands for an investigation a waste of time? Even though the deaths were not investigated, the answer is no. Reporters from four cities subsequently toured Rome and wrote feature stories on institutions. Two reporters followed up their stories with a series of articles on institutions and alternative services in the community. One reporter returned to his city to conduct an exposé of an institution there.

Eventually, nearly a year and a half after the Rome deaths, the governor responded to the publicity about Rome and a state psychiatric center and signed an executive order creating an independent panel of physicians to review suspicious deaths at state institutions.

This chapter has discussed strategies for investigating institutions and community settings. The next chapter explains how to understand individual case records.

CHAPTER V. UNDERSTANDING CASE RECORDS

Making sense out of case records can be a formidable undertaking.[5/] After even a short period, a resident's records will be filled with page upon page of obscure and seemingly trivial information -- cryptic statements, illegible scrawlings, jargonistic reports, self-serving staff accounts of incidents and other fragmentary materials. But hidden within the records is the story of a person's experiences at the facility. If you know what to look for in records and how to read them, the story -- or at least key elements of it -- will unfold.

Reading case records can be a time-consuming task. Take a box of paperclips with you. As you come across important entries, paperclip the page. You can photocopy the pages later or transcribe the entries onto paper or, even better, index cards. If you transcribe entires, be sure to record their source -- name of record, page number and date -- so you can return later to verify or supplement the information.

Contents

When reviewing records, start by familiarizing yourself with what they contain and how they are organized. The organization and content will vary from state to state, and sometimes even from facility to facility. However, case records usually include the following kinds of reports and documents:

Administrative/Legal Records. Generally, a section is devoted to administrative and legal matters. This section will contain documents like commitment papers and letters to parents or guardians.

5/ This guide is designed for reading institutional records, but it can alsc be used for examining the records of persons placed in community residences.

Admission Notes. These will contain background information on the resident when admitted to the facility: current skills, family information, circumstances leading up to the admission, etc.

Incident Reports. These are reports on incidents involving the individual; for example, reports on runaways, injuries, accidents and assaults on or by the resident. These are important sources of information concerning a resident's care.

Medical Examinations. These include routine physical exams, consultation reports and records on treated illnesses or injuries.

Doctor's Order Sheets. This is an ongoing record of medications and treatment procedures prescribed by physicians. The Doctor's Order Sheets will include orders for behavior control drugs, isolation and restraints (if used) and should be read carefully.

Treatment and Medication Record. This is a record kept for every resident on the living unit or ward. It specifies the medication or treatment prescribed by the physician for the resident and contains a place for staff to record when the medication or treatment was given.

Professional Evaluations. Generally, the records will contain professional evaluations and recommendations for the resident by, for example, occupational therapists, social workers, physical therapists, psychologists, speech and hearing specialists and others. Read carefully the recommendations made by professionals.

Ward Notes (Progress Notes). These are maintained on every resident by direct-care staff. The ward notes will include entrees on out-of-the-ordinary events and incidents: sicknesses, unusual behavior, visits by outsiders and so on.

Individual Habilitation Plans (Treatment Plans). Under the federal Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. §§ 6001-6081, every resident must have an individual habilitation plan, specifying long-term goals and intermediate objectives relating to the attainment of such goals. A daily activity schedule sometimes accompanies an individual's habilitation plan. The individual habilitation plan is an extremely important document and should be read carefully.

Individual Education Plans. Under the federal Education for All Handicapped Children Act, PL 94-142 (20 U.S.C. §§ 1401-1461), every school-age child, including residents of institutions, must have an individual education plan that includes a statement of long-term goals and short-term objectives as well as a statement of the specific educational services to be provided to the child.

What To Look For

The purpose of reviewing institutional records is to monitor the quality of care received by an individual resident. You will be looking for instances of poor care (diseases, injuries and untoward events), development of problem behaviors, drugging and undue restraint, as well as evidence that the person has received appropriate treatment (programming and education).

Diseases, Injuries and Untoward Events

All people are exposed to illnesses and accidents in the course of their daily lives. Because of overcrowding, inadequate staffing and stressful environmental conditions, institutionalized persons are exposed to a greater number of physical harms. You should carefully examine records for diseases, injuries, runaways and other events.

Documentation of accidents, injuries, untoward events and illnesses will be found in incident reports, ward notes, medical examinations and doctor's order sheets. Incident reports are the best sources of information on major accidents, illnesses and runaways. These reports will describe what happened to the resident, who witnessed the incident and whether the incident was reviewed internally (i.e., by officials). While written by staff, generally in a self-serving manner, these reports will contain the basic information on the incident. The ward notes will have entries on major as well as minor events (e.g., cuts, scratches, vomiting, etc.). The medical examinations will contain a physician's diagnosis of injury or illness, while the doctor's order sheets will describe the treatment prescribed. Often you will need to consult all of these sources of information to obtain a complete picture of what happened to the resident. But do not be surprised if the various accounts contradict each other.

Here are some specific things to look for in these records:

* Lacerations, bruises, broken bones inflicted on the resident by him/herself or others. When people are provided with proper supervision and appropriate programming, these injuries do not occur in great numbers. At a minimum, institutionalized persons have a right to protection from harm, including the harm resulting from self-abuse.

* Runaways. Repeated instances of running or wandering away are indicative of either a repressive environment (residents want to escape) or inadequate supervision (for people requiring intensive care).

* Institutional diseases and parasites. Certain diseases are endemic to institutions. They result from crowded and unsanitary conditions. Hepatitis, recurring staph infections, influenza epidemics and parasites like scabies, pinworms and ringworm -- all are evidence of poor care.

* Check the time lapse between the first note of a condition in the records (see the ward notes) and when the condition was treated by a physician. Needless to say, injuries and illnesses should be treated as soon as possible.

Deterioration and Problem Behaviors

Inadequate programming and poor conditions may actually cause disabilities and aggravate problem behaviors. Check the admission notes, initial medical examinations and professional evaluations and the early ward notes to identify problem behaviors a resident had when he or she entered the institution (although these records commonly underestimate a person's abilities). By checking recent examinations, evaluations (especially psychological evaluations) and habilitation or treatment plans, you will get a sense of what problem behaviors have developed at the institution.

Some specific behaviors to look for:

* Toilet training. It is not uncommon for residents to lose their toilet training at institutions.

* Aggressive or assaultive behavior.

* Rocking and head-banging. Institutional folk wisdom to the contrary, these are not primarily symptoms of mental retardation; they are symptoms of boredom, stress and lack of programming.

* Smearing feces.

* Taking off clothes.

* Running away.

* Eating pica (non-food objects).

When reading records, do not be seduced by victim-blaming perspectives among staff. Keep in mind that the institution is the offender; the resident is the victim.

Drugging

Over-drugging in institutions is a documented fact. Many people are drugged solely to control their behavior, as a substitute for programming and as a convenience to staff. The Physician's Desk Reference (PDR) is a basic reference book on medications, containing the manufacturer's recommended usage of drugs, recommended dosages and a list of adverse side effects. The PDR can usually be obtained only through a physician or a medical library (but check medical or nursing school bookstores).

The doctor's order sheet will contain the drugs and their dosages prescribed by physicians. The treatment and medication record indicates that the drugs were actually administered by staff and is usually easier to read, understand and follow.

Some drugs, namely Phenobarbital and Dilantin, are used for seizure control and are warranted for people with an active seizure history. Because they may have adverse side effects -- Phenobarbital can have a tranquilizing effect and Dilantin can cause gum deterioration -- they should be carefully monitored.

Tranquilizers, sedatives and stimulants are often used for behavior control. The following is a list of behavior-control drugs commonly used at institutions:

Product (Trade) Name	Generic (Chemical) Name
Thorazine	Chlorpromazine
Plexonal	Sodium phenylethyl-barbiturate
Trilafon	Perphenazine
Prolixin	Fluphenazine hydrochloride
Haldol	Haloperidol
Quide	Piperacetazine
Ritalin	Methylphenidate hydrochloride
Stelazine	Trifluoperazine hydrochloride
Serentil	Mesoridazine besylate
Dexedrine	Dextroamphetamine sulfate
Mellaril	Thioridazine
Sparine	Promazine hydrochloride
Valium	Diazepam
Chloral Hydrate	Chloral hydrate
Dalmane	Flurazepam hydrochloride
Amphetamines	Chlordiazepoxide hydrochloride

Here are some things to look for in regard to institutional drugging:

* No behavior-control drug should be prescribed without a clear therapeutic purpose and unless alternative, less restrictive means (e.g., programming, counseling) have been attempted. You should look for evidence of why the drugs are prescribed (statements such as "he is under sedation to keep him quiet and from bothering others" are indicting) and what other means have been explored.

* Both seizure-control and behavior-control drugs should be carefully monitored. Check the medical examinations and doctor's order sheets. Blood levels of some drugs should be checked periodically (at least once a year); staff should be instructed to observe the resident for adverse side effects; prescriptions should be halted periodically to examine whether residents still need them (this is called a "drug holiday"). Residents receiving Dilantin should have routine dental checks.

* Some drugs regularly prescribed for mentally retarded persons in institutions are not indicated for behavior control of persons with mental retardation. According to the PDR, Quide, Trilafon and Prolixin -- all powerful drugs -- have "not been shown effective in the management of behavioral complications in patients with mental retardation."

* Check for combinations of behavior-control drugs prescribed at the same time. The PDR generally lists which drugs should be used "with caution" in combination with one another: two or more phenothiazines (Thorazine, Mellaril, Serentil, Quide, Stelazine, Prolixin, Trilafon and others); Ritalin and Phenobarbital; and phenothiazines and barbiturate derivatives (e.g., Plexonal).

* Check the PDR to see if drugs have been prescribed in dosages higher than those recommended by the manufacturer.

* Examine ward notes and medical examinations for the adverse side effects of drugs. All of the behavior-control drugs carry side effects, some of which are serious. Check the PDR. Valium may cause changes in saliva (resulting in congestion, choking and increased susceptibility to pneumonia), blood disorders, increases in muscle spasticity, nausea and fatigue. Psychotropic drugs, especially the phenothiazines, can cause impaired mental and physical abilities, neurological disorders, agranulocytosis (lowered white blood cell count and increased susceptibility to infections), skin-eye reactions, persistent constipation, insomnia, seizures, sleepiness, restlessness, lethargy, anxiety and confusion. Two serious side effects of the long-term use of phenothiazines are neurological disorders known as persistent tardive dyskinesia and extrapyramidal disorders. Persistent tardive dyskinesia is a generally irreversible condition involving involuntary movements of the jaw, face, tongue or mouth, sometimes accompanied by involuntary movements of the arms and legs. Extrapyramidal disorders include the following specific symptoms: quivering, restlessness, impaired muscle tone (distonia), contraction of neck muscles, stiff neck, arched position of the body, involuntary fixation of the eyeballs (oculogyric crisis), tremors, muscular rigidity and loss of muscle movement (akinesia). Persistent tardive dyskinesia and extrapyramidal disorders resemble Parkinson's disease and are sometimes treated with drugs used for Parkinson's (e.g., Artane).[6/] If you find these symptoms described in a resident's records, you should have him or her examined immediately by an independent physician.

6/ In reviewing an earlier draft of this manual, John Cooledge MD, pointed out that although Artane is sometimes used to treat tardive dyskinesia, there is a growing medical literature indicating that this drug may actually aggravate tardive dyskinesia.

Restraints and Isolation

Restraints include any device which limits a person's freedom of movement within a living area. Camisoles, straitjackets, ties, restraining sheets, bubble-top or cage-top cribs, shackles and mitten-like coverings over the hands are forms of restraint. Even wheelchairs are sometimes used to restrict the movement of residents who are partially ambulatory. The use of restraint is an extreme measure, justified only in extreme circumstances and after less drastic means have been explored.

Isolation, or "time-out" in current euphemism, means solitary seclusion of a resident in a locked or unlocked room.

Records of restraint and isolation should be found in the doctor's order sheets and ward notes. Here are some specific things to look for:

* The purpose of restraint or isolation. It should never be punishment.
* Whether less restrictive means have been explored. Has the person received intensive programming to deal with problem behaviors?
* Policies regarding restraint and isolation. Who can authorize the use of restraint or isolation? (Ward staff should not have the authority to restrain or isolate residents.) How often is the person placed in isolation or restraint? Is the person checked regularly while in restraint or seclusion? Are limits placed on the amount of time a person can be in restraint or isolation? The same questions should be asked regarding the use of helmets to prevent residents from biting others or from injuring the head during falls.

Programming

Records relating to programming will be found in medical examinations, professional evaluations, ward notes and habilitation or treatment plans. Start by reviewing medical examinations and professional evaluations to learn what has been recommended for residents. (Unfortunately, institutional professionals sometimes recommend only the services that are available, rather than those

which residents need.) In medical examinations, check whether corrective devices, hearing aids, dental care or dentures, prosthetic devices or orthopedic aids (e.g., special shoes) have been recommended and whether these have been provided. In professional evaluations, examine what kinds of psychological, occupational therapy, physical therapy, recreational, audiological, speech and other services have been recommended for residents. Pay special attention to physical therapy recommendations for nonambulatory or physically disabled residents. Severely physically disabled residents may require special positioning, range of motion exercises, physical therapy and individually fitted wheelchairs to prevent bed sores, muscle atrophy, bone deterioration and chronic congestion problems.

According to the federal DD Assistance and Bill of Rights Act (42 U.S.C. §§ 6001-6081), every resident of publicly funded institutions and community residences must have an individual habilitation plan (IHP). The IHP must include a statement of the habilitation goals and the services to be provided to the resident. The IHP should incorporate the recommendations contained in professional evalautions. By law the IHP must meet the following requirements:

* The IHP must be in writing.
* The IHP must be developed jointly by the institution's or agency's representative, the resident and, where appropriate, the resident's parent or guardian.
* The IHP must include a statement of long-term habilitation goals and short-term objectives relating to the attainment of those goals.
* The objectives in the IHP must be specific, stated in sequence and expressed in terms of behaviors or measurable indicators of progress.
* The IHP must describe how the objectives will be achieved and the barriers which might interfere with the achievement of the objectives.

* The IHP must state objective criteria and an evaluation procedure and schedule for determining whether the objectives are being achieved.
* The IHP must provide for a coordinator responsible for implementing the plan.
* The IHP must describe in clear language the specific services to be provided.
* The IHP must identify which agency will provide the services.
* The IHP must describe the personnel and their qualifications to provide the services.
* The IHP must state when the services will begin and how long they will be provided.
* The IHP must state the role and objectives of all parties involved in implementing the plan.
* The IHP must be reviewed annually.
* The person and/or the guardian must have the opportunity to review the plan and participate in its revision.

IHPs are sometimes accompanied by daily activity schedules. Check these schedules and the ward notes to monitor the extent to which the IHP is being implemented.

Every resident has a right to programming, treatment and habilitation appropriate to his or her needs. The IHP should act as a vehicle for ensuring vindication of that right. However, services described in an IHP too often exist more on paper than they do in reality.

Education

According to PL 94-142 (20 U.S.C. §§ 1401-1461), all school-age children have a right to a full-time publicly supported program of education appropriate to their needs. Under PL 94-142, every handicapped child must be provided with an individual education plan (IEP) to assure his or her right to an appropriate education.

The IEP must meet the following requirements:

* The IEP must be developed jointly by school district representatives, the child's parents and, where appropriate, the child.

* The IEP must be developed within 30 days of the time the child is determined to need special education services.

* The IEP must be in writing.

* The IEP must be developed, reviewed and revised at least annually.

* The IEP must include a statement of the present levels of educational performance of the child.

* The IEP must include a statement of annual goals, including short-term instructional objectives.

* The IEP must describe the specific educational services to be provided to the child.

* The IEP must specify the extent to which the child will be able to participate in regular educational programs.

* The IEP must state when the services will begin and how long they will be provided.

* The IEP must specify objective criteria and evaluation procedures and schedules for determining, at least annually, whether instructional objectives are being achieved.

PL 94-142 also provides for due process procedures by which parents can challenge the contents of a child's IEP. For further information on PL 94-142 and the IEPs, see the federal regulations issued to accompany 94-142 (Volume 45, Code of Federal Regulations, Part 100) and "A Checklist for an Individualized Education Plan."[7/]

7/ Ellen Barnes, Center on Human Policy; also available in both English and Spanish from the DD Rights Center at the Mental Health Law Project, Washington, DC

Conclusion

To obtain a full picture of a person's experiences at an institution, you should turn to other sources of information in addition to individual records. There is no substitute for first-hand observation of living conditions and programs. By carefully observing institutional settings, you can examine the extent to which paper programs are actually implemented. You might try speaking with or casually interviewing staff, residents and other knowledgeable informants. Institutional staff are often frustrated with their roles and eager to talk in private about their experiences.

You also might try to obtain general information on the institution. Most institutions collect data on population characteristics, staffing ratios and ward incidents. You can review written policies on drugs, restraints and isolation to see if adequate safeguards exist. Other sources of useful information will only be available if you are engaged in discovery proceedings in the pretrial stage of a lawsuit. At most institutions, staff maintain daily logs on happenings on the ward.

The more you familiarize yourself with institutional practices and conditions, the more meaningful record reviews will be. You should combine your review of records with observations, interviews (however causal) and readings on the nature of institutional life -- whether academic articles, newspaper exposés or court testimony and rulings. When you put the pieces together, the story will become complete.

CHAPTER VI. IDENTIFYING GAPS IN COMMUNITY SERVICES

Some problems can only be attacked by working for change in the overall direction and design of a service system. Sometimes what is needed is not reform -- for example, hiring additional staff or writing new policies at institutions -- but a total revision in the way services are provided. States must redirect priorities and resources away from a segregated institutional model of services to a humanizing, integrated community model.

One way to monitor a service system is to research the gaps in services and to identify the obstacles to developing community programs. This chapter provides some basic background information for preparing reports on services which should -- but do not -- exist in your state or community.

The Boston task force's 1970 report, The Way We Go to School: The Exclusion of Children in Boston,[8/] and the Children's Defense Fund's recent report, Children Without Homes,[9/] are examples of widely publicized action reports calling national attention to the plight of children in schools and foster care, respectively. While your group may lack the resources and technical expertise to prepare such in-depth reports, less comprehensive surveys can have a major impact on residential services in your state or community by documenting the inadequacies of the system and making recommendations for change.

8/ Task Force on Children Out of School, The Way We Go to School: The Exclusion of Children in Boston. Boston: Beacon Press, 1971.

9/ Jane Knitzer, Mary Lee Allen and Brenda McGowan. Children Without Homes: An Examination of Public Responsibility to Children in Out-of-Home Care. Washington, DC: Children's Defense Fund, 1979.

In 1976, the Center on Human Policy released a short, 26-page report on the status of services in the county encompassing Syracuse, New York.[10/] It included an analysis of the number of people served in institutions and community settings, an estimate of the number of people in need of community services, an overview of a model system of community-based services, a brief discussion of the legal mandates of public agencies and a set of specific recommendations calling for increased planning and coordination on the part of state and county agencies. The report received widespread attention in the local media and human services community and was adopted by a local parent coalition to provide a backdrop for negotiations with state and county officials.

To advocate effectively for community services in your area, you will need three basic sources of information:

1. The current status of services. You can probably obtain public information on the number of people served in institutions and community settings. You might supplement statistical information with descriptive case studies describing the situation of individual persons.

2. The roles of public agencies. You need to know the mandates and the organization of state and local public agencies. For example, which agencies are responsible for planning and coordinating community services? What mechanisms have been developed to facilitate the creation of community programs? What are the major obstacles to establishing community residences?

3. Certain kinds of background information, including needs-assessment estimates and model service systems.

The remainder of this chapter provides background information which you may find useful in preparing action reports or otherwise monitoring public service systems.

10/ Steven J. Taylor. Toward a Comprehensive System of Community-Based Services. Syracuse: Center on Human Policy, 1976.

Estimating Needs

Estimates of the prevalence of persons with developmental disabilities vary widely. For mental retardation alone, estimates range from 1% to 3% of the general population. "Developmentally disabled" and "mentally retarded" are labels, rather than objectively based categories. For example, in 1973, the American Association on Mental Deficiency revised the statistical definition of mental retardation, thereby enormously reducing its incidence in the population. Some discrepancies and confusion are thus bound to attend any attempt to define or enumerate the number of persons with developmental disabilities who are in need of services.

Burton Blatt,[11/] basing his figures on a series of studies, has estimated that 1% of the population needs special services due to mental retardation, 1% needs them as a result of emotional disturbance and 1% needs them because of moderate or severe sensory or physical disorders. Blatt has also calculated the type of services required by people in each category. His estimates of the needs for services in a hypothetical region with a total population of 500,000 are contained in Table I.

11/ Burton Blatt, "Instruments of change -- the executive." In R. B. Kugel (ed.), Changing Patterns in Residential Services for the Mentally Retarded. Washington, DC: President's Committee on Mental Retardation, 1976; Burton Blatt, Robert Bogdan, Douglas Biklen and Steven Taylor, "From institution to community: A conversion model." In Ed Sontag (ed.), Educational Programming for the Severely/Profoundly Handicapped. Reston, VA: Council for Exceptional Children, 1977.

TABLE I: Estimated Needs for Special Community and Residential Services for Children and Adults in a Model Region of 500,000 Population

Category	% of Total Population in Categories	Est. No. in Category
Major categories		
1. Percent of total population needing special services due to mental retardation	1% of total population: .75% EMR; .20% TMR; .05% SMR	5,000
2. Percent of total population needing special services due to behavior disturbances	1% of total population: .50% severely Ed or SM; .50% moderately or mildly Ed or SM	5,000
3. Percent of total population needing special services due to moderate or severe sensory and/or physical disorders	1% of total population: .03% blind; .08% deaf; .14% severely sensory and/or PH; remainder partially disabled	5,000
Sub-categories		
1. Mental retardation		
a. Individuals in need of special programs in public school at any one time	1% of total school population (125,000)	1,250
b. Individuals in need of only minimum services beyond special programs during school years	50% of entire mentally retarded population	2,500
c. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
d. Individuals requiring other services:		
Nursery and preschool programs	5% of known mentally retarded population	250
Day care programs	5% of known mentally retarded population	250
Sheltered workshop activities, vocational training, adult day activities	10% of known mentally retarded population	500

Category	% of Total Population in Categories	Est. No. in Category
2. Behavioral disturbances		
a. Individuals in need of special programs in public school at any one time	1% of total school population	1,250
b. Individuals in need of only minimum services beyond special programs during school years	50% of entire emotionally disturbed pop.	2,500
c. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
d. Individuals requiring other services:		
Nursery and preschool programs	5% of known emotionally disturbed population	250
Day care programs	5% of known emotionally disturbed population	250
Sheltered workshop activities, vocational training, adult day activities	10% of known emotionally disturbed population	500
3. Sensory and/or physical disorders		
a. Individuals in need of special programs in public school at any one time	1% of total school population	1,250
b. Individuals in need of only minimum services beyond special programs during school years	50% of entire sensory and physically handicapped population	2,500
c. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
d. Individuals requiring other services:		
Nursery and preschool programs	5% of known sensory and physically handicapped population	250
Day care programs	5% of known sensory and physically handicapped population	250
Sheltered workshop activities, vocational training, adult day activities	10% of known sensory and physically handicapped population	500

A Model Service System

Several model service systems have developed in recent years. While the specific components may vary, a model service system includes a full array of residential, educational, vocational and supportive services in the community. Illustrated below is an outline of the basic elements of a comprehensive system of community-based services:

I. Residential Services

1. The Natural Home. Every effort must be made to maintain children at home. This requires a range of support services to children and parents.

2. Family Care. Foster family care traditionally has been the major --and sometimes only -- alternative to institutionalization for mentally retarded persons. At ENCOR, the Eastern Nebraska Community Office of Retardation, alternative living units -- family care bolstered by intensive support services -- serve three or fewer people and form the basic model of residential services.

3. Developmental Maximation Units. These are small community-based residences serving people with severe multiple disabilities or medical needs.

4. Group Homes. Ideally, a group home should serve no more than six people.

5. Supervised Apartments and Apartment Clusters. These are semi-independent living arrangements. Staff provide supervision and assistance and are accessible on an as-needed basis.

6. Co-Resident Apartments. These are apartments shared by disabled and nondisabled persons.

7. Independent Living. People live in their own dwellings and receive support services as needed.

II. Developmental, Educational and Vocational Programming

1. Early Child Development (Infancy and Preschool)

   a. Home visit/teaching programs

b. Infant stimulation programs

c. Integrated nurseries and day care centers (including full day care)

2. Public School Programs (school-age children)

a. Elementary and secondary full-day schooling, offering academic and language development and socialization and life skills

b. Vocational preparation

3. Physical and Occupational Therapy (all ages)

4. Vocational and Skills Training (all ages)

5. Adult Day Training

III. Occupational Placements

1. Supervised Work

2. Work Stations in Regular Industries

3. Placement and Follow-up in Typical Employment Settings

4. Self-Employment

IV. Support Services

1. Training and Counseling for Parents, Foster Parents and House-managers on a Routine Basis

2. Client Counseling

3. Transportation

4. Citizen Advocacy

5. Diagnostic, Information and Referral Services

6. Home Aide Services

7. Medical and Dental Care

8. Recreation and Social Activities

9. Financial Assistance

10. Respite Care

11. Advocacy and Legal Assistance

ENCOR and MORC (Macomb-Oakland Regional Center) are probably the best-known model community service systems. ENCOR was the first truly community-based service system in the nation and is committed to a set of explicit principles, including normalization, the least restrictive alternative (institutions have no place in ENCOR's scheme) and individualization (services are tailored to the individual's needs, rather than vice versa). MORC, which is committed to a similar set of principles, serves a large number of severely and profoundly retarded and multiply disabled persons in the community (about 85 percent of the residents of MORC's community-living arrangements fall into these categories). For further information on ENCOR, contact Public Education and Information Office, ENCOR, 885 South 72nd Street, Omaha, Nebraska 68114; for information on MORC, contact the Macomb-Oakland Regional Center, 36358 Garfield Road, Fraser, Michigan 48026.

Planning and Coordination

Too often, deinstitutionalization has simply meant either reinstitutionalization or "dumping." Institutional residents have often been placed in large nursing homes of two or three hundred people or in group homes, foster homes and boarding homes that provide little more than bed and board. The goal of deinstitutionalization should not be simply to move people from one location to another or from a custodial-care facility to a non-care facility. Rather, the goal must be to move people from segregated, dehumanizing institutions to normalized, community-based settings. How is this to be accomplished?

Moral or legal mandates to release people from institutions will not alone result in the development of a system of service in the community. Nor will a system evolve through the voluntary actions of public or private agencies. Only through a planned, coordinated approach to deinstitutionalization can a system of services be put into place.12/

A single agency must be responsible for planning and coordinating activities:

* To conduct thorough needs assessments. How many people require residential placements? How many need transportation or home-aide services? How many require training in self-help skills, work habits and vocational activities?

* To prepare long-term and short-term plans for deinstitutionalization and the development of community services. The planning must include a determination of the nature and number of community services to be developed, identification of the agencies which will operate services and a timetable for the implementation of services.

* To delineate the various funding mechanisms available to support community programs. A variety of federal sources of funding is available to finance the construction and operation of community services, including Title XIX Medicaid (this source may be used to fund small community-based residential services in addition to large institutions), Housing and Urban Development loans and grants, Supplemental Security Income and federal Developmental Disabilities money. (The Federal Programs Information and Assistance Project publishes a series of excellent manuals on federal sources of funding for programs for the developmentally disabled. For information, contact the project at 1522 K Street NW, Suite 1030, Washington DC 20005.) A central agency must identify sources of funding and application procedures and assist in cutting through the red tape involved in obtaining funds.

* To provide technical assistance to potential service providers. Some agency must identify the steps necessary to establish a community program and assist service providers in writing proposals, obtaining operating certificates, preparing budgets, selecting staff and other practical matters.

12/ Blatt, Bogdan, Biklen and Taylor, "From institution to community: A conversion model." Cited above. Many of the ideas discussed in this section were originally contained in this article.

* To act as a single point of entry into the system, providing information and referral as well as follow-up for people in need of services.

* To evaluate and monitor community services according to accepted professional standards.

* To provide community education on the nature of developmental disabilities. There must be a planned effort to overcome community prejudice and resistance to deinstitutionalization.

* To provide for the redeployment and retraining of institutional staff.

In the absence of a planned, coordinated approach, deinstitutionalization will fail to yield its expected positive results and may produce a powerful backlash.

The preceding chapters have been devoted to monitoring strategies -- how to "watchdog" institutions, community residences and service systems. The concluding chapter of this manual deals with advocacy strategies used in conjunction with monitoring activities.

CHAPTER VII. ADVOCACY STRATEGIES

The purpose of monitoring is to bring about changes in the way services are provided. What you learn through collecting public information, observing facilities, sponsoring investigations, reading records and surveying community services must be communicated to others -- the public, elected officials, agency administrators and staff and, of course, consumers. As suggested throughout this manual, you should try to document your observations and findings in a written report. But then what? How do you get the most out of your monitoring efforts? Here are some suggestions:[13/]

* Media Coverage. Hold a press conference to announce an action report or demands for an investigation. Press releases are generally better for less dramatic events, such as formation of a monitoring committee. By getting coverage -- newspaper articles and interviews on radio or television talk shows -- you both increase public awareness of your issues and force officials to account for conditions, policies and practices. Media coverage also increases the visibility of your group and establishes your reputation for action, leading to calls and letters from consumers and staff members with inside information and complaints. Press coverage thus helps to identify potential plaintiffs for system-changing litigation.

* Legislative Testimony. Monitoring reports provide excellent background information for legislative testimony. They demonstrate that you have researched your issues and provide documentation to support your position.

* Public Forums and Hearings. You can release your report by sponsoring public forums or hearings on residential services for people with developmental disabilities. (Be sure to invite the press.) In one community, more than 15 groups sponsored a public forum at which local and state agency heads were asked to respond to a report on gaps in community services. Among other things, the report documented the lack of coordination between local and state officials as well as the tendency of both

13/ See Douglas Biklen, Let Our Children Go: An Organizing Manual for Advocates and Parents. Syracuse: Human Policy Press, 1974. This provides more specific information on the strategies discussed below.

to engage in buck-passing. The public forum, attended by hundreds of consumers and covered by the press, forced the officials to clarify their respective responsibilities.

* Newsletters. Many groups publish regular newsletters for their memberships. A newsletter can contain a regular column on ongoing monitoring efforts.

* Negotiations.[14/] What you learn through your monitoring can provide a backdrop for negotiations. For instance, data on public expenditures for institutions versus alternatives can be used to support your demands for increased resources for community services. Information obtained through case records can be used to advocate for an individual person's rights. Observational data can be used to check the progress of administrative efforts to rectify deficiencies at residential settings.

* Litigation. Information collected through monitoring can be used to support litigation on behalf of the residents of institutions or community settings. Some information can be introduced in court while other information will identify conditions or practices to be examined by expert witnesses.

Like other strategies, monitoring efforts must be well planned and coordinated. Attorneys locate plaintiffs, decide on legal strategy, examine potential evidence, consider prospective witnesses and anticipate the other side's line of defense before they go into court. You must go through a similar process before you decide on any specific approach or strategy. Once more, here are some guidelines:

* Map out a set of strategies well in advance. The traditional exposé is a one-shot affair and seldom results in long-term change. To be effective, you must develop a sequence of timely actions. Every action should lead to other actions. For instance, before you announce formation of a monitoring committee, identify its potential members and select people to write reports; decide on how you will release your findings; try to anticipate how agency officials will react to your efforts; explore ways of keeping the pressure on after the reports have been released. The public forum described above was only one of a coordinated set of strategies that included a letter-writing campaign, a consumer "call-in" to the offices of agency heads, two press conferences, an action report and several negotiation sessions.

14/ See Steven J. Taylor, "Negotiation: A Tool for Change." Syracuse: DD Rights Center, 1979.

* Target your efforts. One can become overwhelmed by the massiveness of some problems -- in the area of residential services, the public has backward attitudes, state and local officials pass the buck, elected officials impose financial constraints, staff lack skills, the federal government provides financial incentives (Medicaid dollars) for states to pour resources into institutions and so on. All problems cannot be solved at once, but you have to begin somewhere. Focus your efforts and choose strategies that will demonstrate some signs of effectiveness (although keep in mind that working for change is a long-term commitment). For instance, you might begin by monitoring only certain types of residential settings or by directing attention to local issues and agencies before turning to state matters.

* Be clear about your goals before you take any action. Unless you have a vision of what you want to accomplish, you may only succeed in causing confusion. While focusing largely on institutions, this guide is designed to enable advocates and consumers to work for the creation of community services. From this perspective, the goal of monitoring and investigating institutions is to document how and why they are not humane places for people to live. The message should be clear: The solution to the problems of institutions will not be found in hiring additional staff, shifting administrators or applying other administrative bandaids. The answer can only be found in the development of homes and services in the community.

Any form of monitoring helps to insure the quality of services provided to persons with developmental disabilities. If you accomplish nothing else, you put officials on notice that the abuses of the past -- and, too often, of the present -- will no longer be tolerated. "Out of sight, out of mind" is not true any more. Now, someone is watching.

APPENDIX

OBSERVATION REPORT

GRAFTON STATE SCHOOL AND SAN HAVEN STATE HOSPITAL

NORTH DAKOTA

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June 1979

This report was prepared as part of an on-site consultation visit to Legal Assistance of North Dakota by the DD Rights Center of the Mental Health Law Project with the Center on Human Policy.

This report contains the findings of one-day visits to Grafton State School and San Haven State Hospital, the two state institutions for the mentally retarded in North Dakota. The five-hour tour of Grafton took place on Tuesday, June 12, 1979, and the two-and-one-half-hour tour of San Haven occurred on Wednesday, June 13, 1979.

The report that follows is not intended to serve as a comprehensive evaluation of services at Grafton and San Haven. We visited both facilities for a relatively short period of time. At Grafton, we only toured six of the nine residential buildings. Further, we did not examine records and other materials concerning residents' care, nor did we review facility budgets or program policies.

Our visit was intended to yield a first-hand view of environments and living conditions at the two institutions, with special attention directed toward considerations of human and legal rights. During the visits, we recorded observations of the physical environment, programming, resident appearance, staff-with-resident interactions, staff practices and other features of institutional life.

THE TOURS

Grafton State School is a large institution housing approximately 850 residents. Located on the outskirts of a town of about 6,000 residents, Grafton is surrounded by several large fields, with a graveyard on one side. It has a budget of approximately $17 million for the biennium, according to administrators.

Grafton consists of a series of residential buildings, programming facilities, an administration building, physical-plant facilities and other buildings spread over a large grounds. The buildings vary widely in size, age and design. We

visited nine buildings at Grafton: the professional services building, the canteen, food service and six residential buildings. The residential buildings are described below:

North A. This is a multi-storied building for men. Most of the residents of North A are older and moderately retarded. The floors and wards of North A are similar to one another. Each ward contains a dormitory and a dayroom. There are also some small kitchens and semi-private rooms within North A.

North B. This building, also multi-storied, contains residents of both sexes. Like North A, North B is organized on a dayroom-dormitory model. North B contains some behavior management units.

Annex. This is a small building for predominantly nonambulatory residents.
Wylie Hall. Wylie, a multi-storied building, has four wards: two for the severely and profoundly retarded; and two behavior management wards, one for men and one for women. Each ward contains a large dormitory and a dayroom, in addition to other rooms.

West Hall. West Hall, similar in design to Wylie, contains severely and profoundly retarded women.

Hospital. This is a multi-storied building for residents with medical problems. The hospital contains both semi-private rooms and larger dormitories.

During our tour, we observed few residents using the grounds and playground areas at Grafton, despite warm temperature and sunny skies. One small group of residents watched the installation of a new sidewalk beside the professional services building; another group walked toward the food service building near dinner time; a small number of residents were sitting outside or using the playground facilities. Most residents, however, remained indoors.

San Haven, administratively a division of Grafton, is a small institution containing 265 residents. San Haven is located on a hill overlooking an extremely small town (Dunseith) in a remote part of the state near the Canadian border. San Haven has a budget of $7.5 million for the biennium. Founded as a TB sanitarium, San Haven received its first mentally retarded residents in 1959; the last TB patients were moved out in 1973.

The San Haven institution consists of one large, multi-storied residential building, a cafeteria and many small buildings serving as staff residences (63 of the facility's staff live on the grounds). San Haven's West Wing, organized on a dormitory-dayroom model, contains older residents, most of whom came from Grafton. The East Wing contains nonambulatory residents. Each of the wards on East Wing is one large room. There are four wards in the West Wing and five wards in the East Wing.

Many of the West Wing residents were outside on the day of our visit, sitting in front of the main building. None of the East Wing residents was outside.

Most of our time at San Haven was spent speaking with the head administrator. During our tour, we were hurriedly ushered from one living unit to another, with little opportunity to talk with staff or residents.

GRAFTON: SUMMARY OF OBSERVATIONS

The Physical Environment

While their design varies from building to building, Grafton's wards do not provide an atmosphere conducive to resident treatment and habilitation.

First of all, the wards at Grafton are crowded. With the exception of some semi-private rooms in North A and the hospital, residents sleep, eat and live in the company of as many as 34 other residents. For example, in North A, we found dormitories containing 26 and 30 beds; in North B, the dormitories had 24 and 16 beds; in Wylie, they had 34 or 35 beds; in West, the dormitories had 23 or 33 beds. The size of these wards precludes personal and individualized care (several studies point to ward size as the single most important determinant of resident care) and violates minimal professional standards of adequacy.

Second, the wards lack appropriate and normalized furniture, decorations and amenities. In Halderman v. Pennhurst State School, the federal judge for the Eastern District of Pennsylvania described "normalization" as a "humanistic rennaissance" in services for people with developmental disabilities. Clearly, the rennaissance has not yet spread to Grafton State School (or to San Haven State Hospital). Grafton's wards are strikingly non-normal.

Some of Grafton's wards are devoid of decorations and amenities. In Wylie and West, for instance, furniture and furnishings consist of heavy, durable chairs lined up against the wall in the dayrooms, occasional curtains and old metal-frame beds in the dormitories. On one Wylie ward, we found a mattress on the floor. A staff member explained that a bed frame had been broken and they were waiting for a replacement. Throughout Wylie and West as well as parts of other buildings, there were no carpets, no pictures on the wall, no tables, no dressers or other places for storing personal possessions, no easy chairs, no objects whatsoever.

Other wards, while far from homelike, contain some furnishings and decorations. The wards in North A had curtains on the walls and rugs on the floor. There were dressers by the residents' beds and comfortable chairs in the dayrooms. North B and Annex wards had fewer furnishings than North A, but more than Wylie and West. On some North B dormitories, dressers were grouped together away from the beds.

Third, the physical setup of wards is dull, unimaginative and nonnormalized. In Wylie and West, all wards look the same: rows of beds in the barren dormitories, separated only by four-foot-high concrete-block partitions; chairs lined up against the wall; large observation windows facing from the staff offices into the dayrooms and dormitories. In the other buildings, beds and

chairs are similarly arranged. Staff desks are placed by the dayroom doors, detracting from any efforts to make these rooms homelike.

Fourth, with the exception of a small number of semi-private rooms, Grafton facilities are utterly lacking in privacy. Dayrooms, dormitories, dining facilities, bathrooms -- all lack privacy. Throughout the institution, bathroom doors, when they exist, are left open, leaving residents in plain view of any passersby, including staff members of the opposite sex. Many bathrooms lack toilet stalls. Further, staff members frequently enter bathrooms occupied by members of the opposite sex. Some bathrooms were also dirty; toilets were unflushed.

Residents' Appearance and Possessions

While many, if not most Grafton residents seem to be provided with normal clothing, some, especially those in West and Wylie, wear heavy institutional garb -- easy to slip on and off. On one West ward, the vast majority of women residents were not wearing shoes or socks (at approximately 4:30 p.m.). Four Wylie residents were totally naked during our tour; two of those were in dayrooms.

Grafton residents lack many of the possessions -- including necessities -- that other people take for granted. Extremely few wore eyeglasses; many had neither teeth nor dentures; almost none had jewelry, hearing aids or watches. There were extraordinarily few personal objects in the dayrooms and dormitories. There were no personal possessions or objects in West or Wylie (or even dressers or other places to store objects). Those objects that were to be found were typically inappropriate for the residents' age. For example, North A had occasional stuffed animals on the wards -- for older men.

Grafton residents are made to look different from other people. Many residents wore baggy clothes. Many also had a disheveled appearance, indicating inadequate training in self-help skills. Hair styles were remarkably standardized -- men's hair very short, women's hair somewhat longer.

Basic amenities are lacking in the wards at Grafton. We did not observe bathrooms in North A or the Hospital, but bathrooms in the other buildings universally lacked toilet paper, towels, soap and sometimes toilet seats.

Restrictions on Liberty: Restraints and Control

There are various forms of restraint placed on the freedom of movement of Grafton residents. Wylie, West and at least some parts of North B are locked. Rooms within wards, notably dormitories, are sometimes locked as well. In discussions with staff, we found no evidence that residents are provided with due process safeguards to prevent undue restrictions -- in the form of locked living units -- on their fundamental right to liberty.

Wylie, West and North B contain isolation cells, euphemistically called "time-out" rooms at the institution. Some of those small rooms contain beds; others do not. We observed one Wylie resident sleeping in an isolation cell. A staff member stated that this man preferred to be in isolation. According to staff, residents may be placed in isolation as a punishment for offenses such as attempting to run away.

Some states and federal courts have outlawed the use of isolation cells; North Dakota obviously has not. Other states limit use of isolation through restrictive policies (i.e., by requiring a physician's orders and by placing limits on the amount of time a resident may be placed in isolation). According to staff, there are few limitations placed on the use of isolation at Grafton.

One building charge explained that the building charge or assistant building charge can authorize placing a resident in isolation. She further explained that some residents have standing orders for isolation. Staff can seclude residents at their own discretion. This same building charge was unaware of any institutional policy limiting the amount of time a resident can spend in isolation.

Staff also seclude residents in locked dormitories during the day. We came across two residents isolated in this matter; one a woman in West, one a man in Wylie. Both were described by staff as "troublemakers."

Many types of restraining devices are used at Grafton. The most prevalent form of restraint is the use of shackles -- heavy leather and metal devices -- a practice that can only be described as medieval. Wylie and West dayrooms contain wooden slats on the wall to which shackles can be attached (the slats have been removed on some wards). Two residents were shackled to the wall on our visit. One woman in West was shackled into a chair. One man in Wylie was naked and shackled to the wall by his ankle. Feces were smeared on the wall near him. One staff member explained why this man was restrained: "He's unsteady on his feet. He also runs around bothering the other residents." The staff member added: "We let him out of the shackles several times a day." Perhaps due to our presence, the staff eventually released this man, dressing him in a pair of undershorts. Another man -- naked and alone -- was shackled in bed in a locked West dormitory. Other sets of shackles were attached to beds and walls throughout West and Wylie. On one West ward, a staff member explained that four women residents were shackled to their beds every night.

Other Grafton residents are simply tied to chairs with cords or rags. We saw many residents tied to chairs and unfitted wheelchairs. One Wylie resident

was tied to a wheelchair around the waist and both ankles. The front of his pants was wet with urine. Staff members made no attempt to change his clothes.

We did not observe any residents in straitjackets or camisoles, but we did see evidence of their use. Several were lying on beds in the Wylie dormitories.

We saw many residents wearing white helmets during our tour. These are presumably used to prevent head injuries when a resident falls, given the institutional environment (i.e., uncovered terrazzo floors and durable furniture) and lack of adequate supervision. The use of helmets is an extreme measure, justified only in extreme circumstances.

Many West and Wylie residents were also wearing mitten-like coverings over their hands, apparently to keep them from scratching themselves. On one West ward alone, six residents' hands were covered in this manner.

Without an indepedent medical review, we cannot determine whether tranquilizing drugs (e.g., Thorazine, Mellaril, Valium) -- chemical restraints -- are used as a substitute for programming at Grafton. However, we were informed that 50-60 percent of all Grafton residents receive one or more tranquilizing drugs. We also found evidence of possible negative side effects: listlessness, sunken eyes, extrapyramidal symptoms, skin reactions. The use of Dilantin (prescribed for seizure control), unmonitored and unaccompanied by an aggressive dental care program, might also account for the poor state of many residents' teeth.

Harm and Deterioration

Grafton residents, or at least many of them, are subjected to various forms of harm, including deterioration. Some forms of harm, such as physical assault, are obvious; others are more subtle.

Crafton residents live under crowded and unhygenic conditions. These conditions facilitate the spread of infectious diseases and parasites.

West and Wylie residents (and probably others) live under the danger of physical assault. Staff at these buildings pointed out many assaultive residents. Many residents apparently abuse themselves as well. Seemingly all West and Wylie residents are covered with bruises, scars and lacerations.

We observed countless instances of resident rocking and head-banging in Wylie, West, North B and the Annex. Rocking, headbanging, assault and self-abuse are not symptoms of mental retardation. They are symptoms of lack of stimulation and boredom.

Grafton wards are not only overcrowded but also understaffed, according to minimal professional standards. Most wards had two or three staff and one had only a single staff member for more than 30 severely and profoundly retarded adults. In North A, 26 staff are assigned to care for 126 residents. We were informed by one supervisor that only two staff are assigned to North A at night -- to care for all 126 residents located on four different floors.

The staff we did observe were engaged in record-keeping or custodial duties. We saw extremely few resident-oriented activities on Grafton wards. Nor did we witness any significant staff-initiated interaction with residents. Staff members often maintained physical distance from residents. For example, at least one staff member on every West and Wylie ward was working in the glass-enclosed office apart from residents.

Physically disabled residents suffer a substantial risk of deterioration at Grafton. According to staff members, Grafton employs only two physical therapists, far fewer than needed. In North B and the Annex, we saw numerous physically disabled residents crawling on the floor; wheelchairs sat unused.

When wheelchairs were being used, they were not fitted for the individual resident. Often people in wheelchairs were sitting slumped over.

According to staff members, Grafton's buildings do not meet fire safety standards, thereby exposing residents to yet another potential form of harm.

Programming

As noted above, Grafton wards are characterized by an utter lack of programming or any form of structured activity. We visited the wards during normal programming hours, but observed no programming. We saw one therapy room in North A, but no residents were in the room. Shelves in this room held various children's games and toys -- inappropriate activities for the adult residents of North A. We visited behavior management wards in North B and Wylie. Yet these were indistinguishable from other wards -- no programming or structured activities. On ward after ward, we observed the same: a large number of residents sitting around doing nothing.

According to staff members, Grafton suffers from a shortage of professional staff. There are too few psychologists (three), too few teachers, too few therapists.

SAN HAVEN: SUMMARY OF OBSERVATIONS

San Haven is called a state hospital. It is better described as a human warehouse. As the head administrator commented, residents leave one way -- through death. There are 12 to 15 deaths per year at the facility.

San Haven's West and East wings differ greatly from each other. West Wing wards house 25-30 older, ambulatory residents (one ward has 41 residents). Each ward consists of a long corridor with rooms on either side --

small dormitories (six beds) or semi-private rooms, dayrooms, small kitchens (only 20 San Haven residents eat at the central cafeteria) and bathrooms. The dormitories contain metal-frame beds and, usually, individual dressers. These rooms have window curtains but no rugs. The dayrooms contain televisions, games and easy chairs, usually arranged in a U-shape. Dayrooms and dormitories lack furnishings and objects -- except for stuffed animals and toys. The bathrooms lack doors, toilet paper, soap and towels. Residents using the toilets are in view of people in the corridors.

On the day of our visit, most West Wing residents were outside. There were no structured activities occurring.

East Wing wards, which house nonambulatory residents of all ages, consist of one large room filled with large cribs and bedstands. The wards also have staff desks.

Each East Wing ward contains about 30 severely physically disabled residents. Two or three staff were working on each ward at the time of our visit. The residents were either lying in bed or sitting in wheelchairs. On one ward, 27 residents were in bed and three were in wheelchairs; on a second ward, 28 were in bed and two were in wheelchairs; on a third, 14 residents were in bed and 16 residents were out of bed; on a fourth, six residents were in bed, while 24 were in wheelchairs. On these latter two wards, most of the residents in wheelchairs were pushed together in one part of the room.

The beds lacked special cushions or supports. Most residents were lying on their backs. According to the head administrator, <u>some residents are never placed in an upright position</u>. They seldom, if ever, leave their beds. The wheelchairs -- predominantly white carts -- lacked supports of any kind. No attempt had been made to employ special positioning techniques for residents in bed or in wheelchairs. San Haven has no physical therapists.

Special supportive devices, positioning techniques, range-of-motion exercises and physical therapy are essential to prevent deterioration and even death among severely physically disabled residents. Careless positioning -- being left in a prone position for an extended period of time -- can cause decubitis ulcers (bed sores) or severe congestion that may lead to choking or pneumonia (the leading causes of death at most institutions). The absence of supportive devices, routine exercises and an aggressive physical therapy program can cause deterioration of the limbs -- atrophy of the muscles and decalcification of the bones. East Wing residents are exposed to these and other harms. Many have twisted and deteriorated limbs.

The multi-storied building containing the West and East Wings lacks fire prevention and detection devices. There are no fire alarms or sprinklers. In the event of a fire, it would be impossible for the two or three staff to rescue more than a small handful of the many nonambulatory residents. The administrator admitted that San Haven would receive national publicity if there were ever a fire: "We'd lose a lot of people."

Most East Wing residents were dressed only in T-shirts and several layers of diapers. Two or three were dressed in normal clothing. Two adult women were naked from the waist up. Presumably residents are dressed in several layers of diapers to preclude the need for frequent changing. Wet diapers are not only uncomfortable, but can lead to urine burns and severe bed sores. On the day of our visit, all of the windows were open, with a strong wind blowing into the wards. There was no smell. The administrator commented that there was a heavy smell in the East Wing wards during the colder months.

Various forms of restraint were in evidence on the East Wing wards. Many residents were tied or strapped to their wheelchairs. One child was strapped

to bed. Several children had mitten-like coverings on their hands. Two children were placed in totally enclosed cribs -- cages (considered a form of restraint by the Accreditation Council for Facilities for the Mentally Retarded of the Joint Commission on Accreditation of Hospitals).

San Haven has a chronic shortage of both direct-care and professional staff. The institution has 235 budgeted staff positions (with seven vacancies); 115 staff positions are directly involved in the care of residents. San Haven employs one unlicensed physician. There are no licensed physicians, physical therapists, occupational therapists, psychologists or special education teachers (although the new budget contains slots for one additional physician, one physical therapist and one special educator). The administrator explained that the remoteness of San Haven made it difficult to recruit professional staff.

No real programming occurs at San Haven. As the administrator put it, San Haven is designed for people who "cannot benefit from educational or training programs" -- despite federal court rulings that institutionalized persons have a right to treatment, despite the federal Education for All Handicapped Children Act (PL 94-142), establishing the right of all school-aged children, including those at institutions like San Haven, to an appropriate program of education. We were shown two small therapy rooms -- one filled with ceramic objects waiting to be painted and the other containing some physical therapy devices. Both were empty in mid-morning.

We observed no meaningful activities and no forms of stimulation at San Haven. We did not see one instance of staff interacting with residents. Nor did we see any toys, objects or possessions within reach of the physically disabled residents in East Wing. When asked how two or three staff could possibly feed the many total-care residents in East Wing, the administrator

explained that these residents have no time frame for eating, suggesting that they had nothing else to do (he also stated that many residents are tube-fed).

The administrator acknowledged that there are "shortcomings" at San Haven. He explained that the legislature had recently authorized construction of a new $1.3 million building at the institution to contain storage rooms, a laundry, dietary facilities and recreation rooms. He suggested that this building would enable San Haven to overcome its shortcomings.

CONCLUSION

Grafton and San Haven, though dramatically different in some ways, share certain common elements, among them inadequate programming, shortages of direct-care and professional staff, overcrowding and the use of obnoxious restraining devices.

Both facilities fail to meet minimal professional standards of adequacy. Both are monumental examples of illegality: They deny residents' rights to treatment, to education, to freedom from harm and to humane living conditions. Both institutions have outmoded and unsafe buildings and are located in relatively remote areas of North Dakota, away from the state's population centers as well as from residents' families and from concentrations of professionals and potential volunteers.

Perhaps the problems that plague Grafton and San Haven cannot be solved in the context of the institutional model. They can only be solved through the creation of a well-planned and carefully implemented system of residential, supportive and training programs in the community. Some experts in the field of mental retardation point out that all people with developmental disabilities can benefit from programming and community living in small, homelike community

residences. Model programs in Nebraska and the Macomb-Oakland region of Michigan serve even the so-called profoundly retarded and multiply disabled in the community. Federal court rulings and statutes mandate that services for the developmentally disabled be provided under the least restrictive, most normalized circumstances possible. One federal court in Pennsylvania ordered the state to create community living arrangements for all the mentally retarded residents of one institution.

North Dakota should undertake an aggressive program of returning the residents of Grafton and San Haven to the community. A recent study out of the University of Minnesota found that North Dakota had the highest rate of institutionalization in the country and one of the lowest rates of placing developmentally disabled persons in community residences. By Grafton and San Haven administrators' accounts, federal sources of funding for community programs -- Title XIX, Title XX, Housing and Urban Development grants -- are virtually untapped in North Dakota.

Grafton should be phased out gradually as services are devleoped in the community. San Haven should be closed as soon as possible. Under no circumstances should a new building be built at San Haven. Bandaid approaches will not solve the problems faced by Grafton State School and San Haven State Hospital.

RESOURCES

Evaluation Tools and Checklists:

A Normalization and Development Instrument: A Rating Instrument to Evaluate the Quality of Services to Individuals with Developmental Special Needs. Ann Flynn and Sandra K. Weiss, ANDI, P.O. Box 60964, Sacramento, CA 95860.

Monitoring Service Quality: A Manual for Voluntary Associations. John O'Brien, Georgia Association for Retarded Citizens, 1575 Phoenix Blvd., Atlanta, GA 30349.

Observing Community Residences. Steven J. Taylor and Robert Bogdan, Center on Human Policy, 216 Ostrom Ave., Syracuse, NY 13210.

Observing in Institutions. Robert Bogdan and Steven J. Taylor. Center on Human Policy, 216 Ostrom Ave., Syracuse, NY 13210.

PASS 3: A Method for the Quantitative Evaluation of Human Services. Wolf Wolfensberger and Linda Glenn, National Institute on Mental Retardation, York University campus, 4700 Keele St., Downsview (Toronto), Ont. M3J 1P3 Canada.

Residential Programming for Mentally Retarded Persons: Developmental Programming in the Residential Facility. National Association for Retarded Citizens, 2709 Avenue E East, Arlington, TX 76011.

Take Steps to Look and Learn: A Guide for Observing Residential Facilities. Pennsylvania Association for Retarded Citizens, 1500 N. Second St., Harrisburg, PA 17102.

Standards:

1977 Standards for Institutions for Mentally Retarded or Persons with Related Conditions. (Also see ICF and ICF/MR Survey Report Form--Resident Rights Addendum and Fire Safety Survey Report Medicare--Medicaid.) U.S. Department of Health, Education and Welfare, Social Security Administration. Contact Regional Office HHS.

Pineland Center Consent Decree Standards. Mental Health Law Project, Suite 300, 1220 Nineteenth St. NW, Washington, DC 20036.

Standards for Community Agencies Serving Persons with Mental Retardation and Other Developmental Disabilities. Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals, 875 North Michigan Ave., Suite 2201, Chicago, IL 60611.

Standards for Residential Facilities for the Mentally Retarded. Accreditation Council for Facilities for the Mentally Retarded, Joint Commission on Accreditation of Hospitals, 875 North Michigan Ave., Chicago, IL 60611.

Willowbrook Consent Decree Standards. New York State Office of Mental Retardation and Developmental Disabilities, 44 Holland Ave., Albany, NY 12229.

HUMAN POLICY PRESS Publications

Books

Let Our Children Go by Douglas Biklen, $3.50.
Teach and Reach by Barnes, Eyman & Bragar, $4.50.
Christmas in Purgatory by Blatt & Kaplan, $3.50.
The Origin and Nature of Our Institutional Models by Wolf Wolfensberger, $3.50.
Sticks and Stones Book by Elizabeth Pieper, $4.00.
The Sneely-Mouth Snerds and the Wonderoctopus by Grealish & Grealish, $1.75.
Amy Maura by Grealish & Grealish, $1.75.

Slide Shows

Children Learn Together by Ellen Barnes, $35.
Where the Children Are by Douglas Biklen, $35.
Handicapism by Bilken and Bogdan, $55.
Integration Can Work by Barnes ¢ Knoblock, $45.
The Family Album by Blatt, McNally * Ozolins, $50.

Posters

IQ: The Myth Is Crumbling, $2.00
Give Us Our Rights, $2.00.
Resistance to Change, $2.00.
Free Our Children, $2.00.
Label Jars Not People, $2.00.
I Am Blind Yet I See, Deaf Yet I Hear - Corita, $5.00.
Hi, Friend, $3.00.
If you thought the wheel was a good idea...ramp!, $3.00.
Sticks and Stones Poster, $5.00.
We All Fit In, $3.00.
Any Questions?, $3.00.
Now, Seven Ways to Change...,$3.00.

Make checks payable to Human Policy Press. Send orders to Human Policy Press, P.O. Box 172, Syracuse, NY 13210.

DD Rights Center Publications

Also available from the DD Rights Center of the Mental Health Law Project with the Center on Human Policy:

"Negotiation: A Tool for Change" by Steven J. Taylor, $ .35.

Understanding the Law: An Advocate's Guide to the Law and Developmental Disabilities by Steven J. Taylor and Douglas Biklen, $3.25.

"Principles of Whistleblowing" by Douglas Biklen and Milton Baker, $ .35.

"Vocational Rights" by Douglas Biklen, Patricia Kennedy, John McGuire, Jill Vigdor and Steven Taylor, $. 50.

"Observing Community Residences" by Steven J. Taylor and Robert Bogdan, $. 50.

"Observing in Institutions" by Robert Bogdan and Steven J. Taylor, $ .50.

IEP (Individual Education Plan) Checklist (free of charge) -- also available in Spanish ("Lista de Control para un Plan de Educación Individual") from the Mental Health Law Project (see below)

Bulk rates available on request.

Make checks payable to Human Policy Press. Send orders to the DD Rights Center, Center on Human Policy, 216 Ostrom Ave., Syracuse, NY 13210.

From the Mental Health Law Project, 1220 - 19th Street NW, Washington DC 20036

Combatting Exclusionary Zoning: The right of handicapped people to live in the community, a paperback discussion of zoning litigation and list of cases ($3.50)